DOCUMENT RESUME

ED 399 685 EC 305 016

AUTHOR Schultze, Katie; And Others
TITLE Family Support and Disabilities: An Annotated Bibliography.
INSTITUTION Portland State Univ., OR. Research and Training Center on Family Support and Children's Mental Health.
SPONS AGENCY National Inst. on Disability and Rehabilitation Research (ED/OSERS), Washington, DC.; Substance Abuse and Mental Health Services Administration (DHHS/PHS), Rockville, MD. Center for Mental Health Services.
PUB DATE Apr 95
CONTRACT H133B90007-93
NOTE 69p.
PUB TYPE Reference Materials - Bibliographies (131)

EDRS PRICE MF01/PC03 Plus Postage.
DESCRIPTORS Annotated Bibliographies; Caregiver Child Relationship; *Disabilities; *Family Needs; *Family Programs; Family Relationship; Placement; Printed Materials; Program Evaluation; Public Policy; *Resource Materials; Social Services; *Social Support Groups

ABSTRACT

This annotated bibliography on family support services for families of individuals with disabilities lists 115 print resources published from 1979 through 1994. Most references were chosen for inclusion on the basis of addressing the issue of "whatever it takes" to aid families in caring for an individual with a disability and avoiding placing the individual into a nonfamily setting. Each entry provides the author, title, key words to describe the material, and a brief description. Listings are alphabetical by author within each of four chapters. Chapter 1 lists 14 references from the family support literature not directly related to disability. Chapter 2 includes 25 listings on the personal and interpersonal lives of family members, including relationships with formal and informal support persons. Chapter 3, with 54 references, reviews literature on the service system for families and public policy related to family support. Chapter 4 lists 22 resources that contain descriptions and some evaluations of specific family support programs or services that are or have been in operation. An author index and a subject index are provided. (CR)

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FAMILY SUPPORT AND DISABILITIES

An Annotated Bibliography

Research and Training Center on Family Support
and Children's Mental Health
Portland State University

EC 305016

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FAMILY SUPPORT AND DISABILITIES:
An Annotated Bibliography

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April, 1995

The recommended citation for this publication is:

Schultze, K., Friesen, B.J., Brinkman, D., Flanagan, D., Exo, K., & Butler, T. (1995). *Family support and disabilities: An annotated bibliography*. Portland, OR: Portland State University, Research and Training Center on Family Support and Children's Mental Health.

This publication was developed with funding from the National Institute on Disability and Rehabilitation Research, United States Department of Education, and the Center for Mental Health Services, Substance Abuse and Mental Health Services Administration (NIDRR grant number H133B90007-93). The content of this publication does not necessarily reflect the views or policies of the funding agencies.

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Introduction

The term "family support" has many different meanings throughout the literature on this subject; the meanings tend to vary in both type and circumstance of the family described as well as in the meaning of "support." The focus of this bibliography is family support for families who have members with disabilities, whether they be emotional, behavioral, mental, or physical. However, "family support" is also used to describe interventions to strengthen families who are perceived to be at risk for child maltreatment or other aversive occurrences. Finally, the scope of "family support" can be widened to describe any formal or informal intervention that serves to strengthen any family, whatever their circumstance may be. Thus, the first chapter, **General Family Support**, provides a very brief survey of family support literature which is not directly related to disability. This first chapter may be used as a springboard to the study of family support in a variety of different contexts.

The remaining literature was chosen for inclusion because it in some way addresses the issue of "whatever it takes" to aid families in caring for an individual who has a disability in order that the family may stay together, build strength, and limit or avoid placement of the disabled individual into institutional or other nonfamily settings. Some family preservation literature, where disability may not have been directly related, is included in these chapters because though the individual family circumstances may be different, the goals of strengthening families and preventing placement outside of the home are the same. The essential principles of family support apply whether risk of maltreatment is involved, individual family members have a recognized disability, or both.

In Chapter 2, **Support and the Family**, the focus is on personal and interpersonal lives of family members, including relationships with formal and informal support persons. Chapter 3, **Service System and Policy**, reviews literature on the service system for families as well as public policy related to family support. Chapter 4, **Family Support Programs and Services**, surveys writings which contain descriptions, with some evaluations, of specific family support programs or services that are or have been in operation. Publications in this chapter may serve as a beginning to understanding what specific efforts have been and are being tried under the rubric of family support, as well as some outcomes of those efforts.

The chapter headings are not mutually exclusive, and in many cases a particular publication could have been included in a different chapter. However, for purposes of simplification, each article is found in only one chapter. The index should be helpful in searching for specific subject matter across chapters. Key words which appear above each abstract are referenced in the index. Empirical studies are identified by an asterisk (*) which precedes the reference.

In each annotation, our attempt has been to represent as closely as possible the actual content of each publication, while trying to avoid inserting subjective interpretation or commentary. Where possible, journal abstracts or excerpts from the actual text were used in place of or as a supplement to our own summary information.

This bibliography is not intended to be a comprehensive compilation of works on family support and disability, because, as experienced researchers know, there is always more to be found. However, this text may serve as an excellent beginning to many more specific searches within the field of family support.

GENERAL FAMILY SUPPORT

De'Ath, E. (1989). The family center approach to supporting families. *Child Welfare, 68*(2), 197-207.

Key Words: family center, England, history

The development of family centers in Great Britain by both statutory and voluntary organizations has increased rapidly since the 1970s and has created the opportunity to examine different models for supporting families. This paper provides a brief historical overview, describes some of the current models in practice, and outlines issues arising from this way of working. (Journal abstract)

The author described a previous study which identified three different service models used by family centers: (1) The Client-Focused Model which serves referred clients, has a restricted neighborhood outreach, an emphasis on professionalism, and is usually devoted to one type of client group; (2) The Neighborhood Model with an open door policy, a broad range of clients, flexible staff roles, local participation, and identification with the local neighborhood; and (3) The Community Development Model which encourages residents to perform activities and services themselves, disassociates from the traditional social work model, encourages collective action by residents, and identifies local control of all operations as one of its ultimate objectives.

***Garbarino, J. (1987). Family support and the prevention of child maltreatment. In Kagan, S. L., Powell, D. K., Weissbourd, B. & Zigler, E. F. (Eds.). *America's Family Support Programs: Perspectives and Prospects*, pp. 99-114. New Haven: Yale University Press.**

Key Words: child abuse, social skills, network

The author asserts that large scale success in preventing child maltreatment will involve a measured combination of social control and social nurturance. He identifies five goals that effective family support programs accomplish in reducing the incidence of child maltreatment: 1) improving the social skills of the individual parent; 2) enlarging the resource base of the parent's social network; 3) enhancing the prosocial orientation of the network by linking the parent to mainstream community values and institutions; 4) reducing the degree to which the parent is a resource drain on the network; and 5) providing greater positive surveillance for the family.

The results of several family support studies are briefly reviewed, following which the author identifies eight principles for preventing child maltreatment: 1) prevention goals and their limitations should be stated as precisely as possible; 2) we should recognize that prevention efforts may be effective only under specified conditions; 3) in any overall claims about reducing child abuse in a given community, or across the whole society, we must clearly specify the appropriate base rates and must take into account changes in social and economic conditions and variations in definition and case identification; 4) a complete strategy will involve both generalized primary prevention and programming targeted at high-risk groups; 5) comparable communities can be the targets for intervention so that studies using before/after designs can note and control for broad economic and social effects in analyzing results; 6) evaluation efforts must utilize multiple measures; 7) prevention efforts can include both measures designed to control or restrain destructive patterns and measures designed to replace these destructive patterns with positive patterns that are incompatible with abuse; and 8) two

basic approaches to prevention exist, "patchwork prevention" and "total reform prevention", both may be worthwhile.

Hobart, R., Witkin, D., Payne, C., Weiss, H., Correa, P. & Docknevich, L.H. (no date). *Program to Strengthen Families: A Resource Guide*. Chicago, IL: Yale Bush Center in Child Development and Social Policy, Family Support Project and the Family Resource Coalition.

Key Words: guide, survey, programs

This guide is a collection of information about a variety of family support programs in the United States. It is designed for three audiences: (1) persons interested in starting a new family support program; (2) those concerned with policy and services for children and families; and (3) program evaluators. An introduction traces the evolution of family support programs as well as the implications and problems of this evolution. Each chapter describes selected programs using an overview guide and a detailed description of the program. The eight chapters and programs types are:

(1) Prenatal and infant development;
(2) Child abuse and neglect prevention;
(3) Early childhood education;
(4) Parent education and support;
(5) Home, school, and community linkage;
(6) Programs for families with special needs;
(7) Neighborhood-based, mutual help and informal support; and
(8) Family-oriented day care.

Programs described in Chapter 6 are diverse, ranging from the Parent Specialist Education Program (for a multi-racial population of parents and professionals in Philadelphia) to family, infant and preschool early intervention programs in twenty rural counties in western North Carolina.

***Jenkins, S. (1987). Ethnicity and family support. In Kagan, S., Powell, D., Weissbourd, B. & Zigler, E. (Eds.), pp. 282-293, *America's Family Support Programs: Perspectives and Prospects*. New Haven: Yale University Press.**

Key Words: ethnicity, custom, language, cultural traditions, service delivery, agency policy

"The need for family support is almost universal, but custom, language, religion and a sense of group identity constitute the context of support, which should in turn determine its form...Prevailing concepts of mental health support in the US are essentially Western ideas, often presumed to be universal but actually relevant primarily to the social context in which they were developed. For societies that hold the family to be more important than the individual and the extended intergenerational family more significant than the nuclear family, different assumptions may be needed in developing support programs." (From the author's introduction).

The author of this chapter asserts that ethnicity is a crucial variable in family support programs, the impact of which is examined in a review of two studies regarding ethnic factors in service delivery. In addition, the author reviews 72 family support programs for references to ethnic factors.

***Junge, M. & Ellwood, A. (1986). MELD: Parent information and support groups. *Infant Mental Health Journal, 7*(2), 146-155.**

Key Words: support groups, evaluation, Minnesota

The Minnesota Early Learning Design (MELD) Program provides education to new parents through long-term information and support groups. The program, ongoing since the early 1970s, has been replicated and recognized extensively. This article provides an overview of the MELD model. Program adaptations have led to the development of programs designed to meet the specialized needs of particular parental populations, including adolescents, hearing impaired parents, and parents of handicapped children. The flexibility of this program enables replication in numerous locales and settings. Ongoing evaluations of the model are presented. (Journal abstract)

***Seitz, V., Rosenbaum, L. & Apfel, N. (1985). Effects of family support intervention: A ten-year follow-up. *Child Development, 56*, 376-391.**

Key Words: evaluation, research, program description, cost effectiveness

The delivery to impoverished mothers of a coordinated set of medical and social services, including day care for their children, had effects that were evident a decade after the intervention ended. Intervention mothers were more likely to be self-supporting, and they had higher educational attainment and smaller family sizes than did control mothers. Intervention children had better school attendance, and boys were less likely to require costly special school services than were the corresponding control children. The financial implications of these results were considerable, totaling about $40,000 in extra estimated welfare costs and documented school service costs needed by the 15 control families in the single year in which these follow-up data were gathered. There were no indications that the intervention had lasting effects on the children's IQ scores. The results suggest that family support procedures, including quality day-care, have considerable promise as a general model for intervention programs. (Journal abstract)

***Telleen, S. (1990). Parental beliefs and help seeking in mothers' use of a community-based family support program. *Journal of Community Psychology, 18*, 264-276.**

Key Words: community-based, parental beliefs, help seeking, social support

This study examined mothers' help seeking from a family support program. The mothers' participation in the parenting program was examined within an attributional and social support framework as a function of four factors: (a) the mother's level of child-related stresses, (b) the mother's expressed need for social support in parenting, (c) the mother's attribution of the child's behavior programs to her own efforts, and (d) the mother's belief in her competence as a parent. Mothers participating in a community-based family support program (N = 79) were compared to mothers (N = 56) not using a family support program in a Midwestern town with a manufacturing economic base, high unemployment, and an increasing rate of confirmed child abuse.

The mothers using the family support program reported significantly higher child behavior stresses than did a community sample of mothers with similar aged children.

The mothers seeking help also attributed child behavior problems to their own behavior as a parent. Though the mothers seeking help were not depressed, they believed they lacked competence and expressed more need for social support in parenting than did the comparison mothers not using the program. (Journal abstract)

***Telleen, S., Herzog, A. & Kilbane, T. (1989). Impact of a family support program on mothers' social support and parenting stress. *American Journal of Orthopsychiatry, 59*(3), 410-419.**

Key Words: evaluation, research, stress, support groups, child abuse, availability of support, coping strategies

The authors discuss factors that may have led to similar results in both the parent education group and the mothers' self-help discussion group, describe diverse ways which social support may be given, and raise the possibility that the mothers' perception of social support may be more important than the support itself. In addition, the authors emphasize the need for staff members to: (1) help participants develop a support network within and outside the group; (2) educate parents about the use of social support as a coping mechanism; and (3) enhance the problem-solving capabilities of parents. At a three month follow-up, mothers in both program groups felt less isolation and parenting stress than mothers in the control group.

***Tracy, E. & Whittaker, J. (1987). The evidence base for social support interventions in child and family practice: Emerging issues for research and practice. *Children and Youth Services Review, 9,* 249-270.**

Key Words: evaluation, research, informal support systems, child welfare, literature review

The authors provide a comprehensive literature review of the use of support systems in helping families with children at risk of adverse developmental outcomes. Social support is defined and its impact on child and family functioning is described. The results of several family social support studies are presented along with brief descriptions of the population, variables, and analyses in each. The authors discuss difficulties encountered in attempting to compare and interpret the results of the various studies. Problems arise in comparing studies because of differences in definitions of variables, methods of measurement, and documentation of social support. Interpreting the results of any one study can be difficult as well, because the mechanism by which social support operates is little understood and may vary greatly between individuals.

The authors examine methodological issues in social support intervention research and conclude by discussing six issues of importance for future research in the field: (1) the absence of precise and consistent measures of social support hinders the application of research findings to social network interventions; (2) much of the existing research on social support and social support intervention confounds the presence or absence of environmental resources with the skills needed to make use of those resources; (3) while the research evidence on social support is compelling, much of it is correlational in nature; (4) more research is needed on the organizational requisites for social support interventions for children and families; (5) much work needs to be done in adapting useful evaluation technologies to include measures of the environmental context such as the client's perception of support available, or rating of social interaction in a given time period; and (6) researchers should be aware of possible political and social

ramifications of their findings and should take steps to see that they are not misinterpreted or misused.

Weiss, H. (1989). State family support and education programs: Lessons from the pioneers. *American Journal of Orthopsychiatry, 59*(1), 32-48.

Key Words: availability of support, policy, program description, service planning, service delivery

Thousands of communities have initiated family-oriented prevention programs providing a variety of types of social support over the last twenty years. State governments are currently considering and implementing preventive family support and education programs. The author describes four state efforts, two of which began as pilot programs in Maryland and Connecticut, and two statewide programs established by the legislatures in Minnesota and Missouri which are available to all parents with young children.

The author outlines five factors contributing to state policy makers' interest in family support and education: (1) growth of awareness that parental attitudes and behavior and the family context are important in child development; (2) evidence from longitudinal evaluations of the effectiveness of early childhood education programs; (3) social, economic, and geographic factors contributing to an awareness of the considerable stress and isolation of many families; (4) the capacity of family support and education programs to reinforce the primary role given to the American family by citizens throughout the political spectrum; and, (5) the heightened influence of state governments, which has encouraged governors, legislators and public administrators to become "entrepreneurial" and to build coalitions to support education and human services.

The author's overview of state initiatives is coupled with a broad description of all four state programs. She includes key information about program development and implementation as well as the effects of growth and contraction in these programs. Five areas of future challenge to family support and education programs are identified.

Weissbourd, B. & Kagan, S. (1989). Family support programs: Catalysts for change. *American Journal of Orthopsychiatry, 59*(1), 20-31.

Key Words: history, evaluation, service delivery, parent/professional collaboration

The authors describe the history of family support as an outgrowth of the social service and self-help movement, defining family support as "... services to families that empower and strengthen adults in their roles as parents, nurturers and providers." A discussion is presented regarding the preventive nature of family support programs, an ecological approach to family and community, and a developmental view of parenting. Promising results of family support programs are discussed, as well as challenges encountered in evaluating these programs.

Whittaker, J.K. (1991). The leadership challenge in family-based services: Policy, practice, and research. Families in Society. *The Journal of Contemporary Human Services, 72*(5), 294-300.

Key Words: policy, family-based services, practice

The author describes a significant change in values and philosophy that is taking place in the field of family-based services. The old model for family-based services consisted of: (1) categorical services; (2) a child rescue philosophy; (3) an unswerving faith in personalistic psychology as the key to diagnosis and treatment; and (4) a "hands off," or at least segregated, approach toward work with families, particularly parents. The new model for home-based services consists of: (1) establishing a service continuum; (2) promoting competence and meeting basic developmental needs of children and families in "normalized" settings by teaching practical life skills and by providing environmental supports as opposed to uncovering and treating underlying pathology; (3) consideration of services as family supportive and family strengthening, not as "child saving"; and (4) the reemergence of the person-in-environment perspective in theory, empirical research, and clinical practice as a foundation for intervention design.

Whittaker, J.K., Schinke, S.P. & Gilchrist, L.D. (1986). The ecological paradigm in child, youth, and family services: Implications for policy and practice. *Social Service Review, 60*(4), 483-503.

Key Words: policy, ecology, social support, life skills

This paper identifies and explores the implications of the ecological paradigm for child, youth, and family services. Historical and theoretical roots of the "person-in-environment" configuration are examined along with recent empirical evidence that suggests the complementarity of "life skills teaching" and "social support facilitation" as elements of effective service programs for children, youths, and families. Implications are drawn for policy development and implementation as well as for the design of service programs. (Journal abstract)

Zigler, E. & Black, K. (1989). America's family support movement: Strengths and limitations. *American Journal of Orthopsychiatry, 59*(1), 6-19.

Key Words: evaluation, public policy, program description, service planning

This is the first of four articles in this issue which examine the family support movement. The authors present a brief overview of the movement and a discussion of the growing need for family support resulting from economic, social and geographic stresses. The strengths and limitations of grassroots and university-based research programs are explored. The article concludes by examining existing and potential sources of public and private funding for these programs; an extensive reference list is provided.

SUPPORT AND THE FAMILY

Aaronson, M. (1989). The case manager-home visitor. *Child Welfare, 68*(3), 340-346.

Key Words: in-home services, case management, home visitors

The author explains the importance of the caretaking environment, reviews the home visitor experience, and describes the combined case manager-home visitor role. Characteristics of model case manager-home visitor programs in Massachusetts, Maine, Utah, and Washington are described. The author concludes, "Developing case manager-home visitor positions, whether nurses or other relevant professionals for the interventions, should be explored as one viable method of serving those in need. What may seem to be a relatively costly program at the outset may pay large dividends in the long run: (1) to families in improved quality of life; (2) to communities in reduced need for providing later community services; and (3) to society in improving the possibility that someday the children served will make a contribution to society instead of developing lifelong dependency and need of care."

***Baker, B.L., Blacher, J. & Pfeiffer, S. (1993). Family involvement in residential treatment of children with psychiatric disorder and mental retardation. *Hospital and Community Psychiatry, 44*(6), 561-566.**

Key Words: residential treatment, children, developmental disabilities

Objective: The goals of the study were to determine the extent of family involvement with children in residential treatment settings, to examine whether involvement diminishes over time, and to examine the relationship between involvement and the child's diagnosis as well as the demographic characteristics of the child and the family.

Methods: Staff rated the level and frequency of family involvement with 234 children, aged five to 19 years, living in three residential treatment centers. The children were grouped according to three diagnostic categories: psychiatric disorder, mental retardation, and dual diagnosis of psychiatric disorder and mental retardation.

Results: Almost one-third of the children had no family contact, and about 50 percent had three or fewer contacts per year. The level of family involvement was lower with dually diagnosed children than with children who had only psychiatric disorder or mental retardation. Level of involvement was also related to the driving time between the family home and the residential facility and to socioeconomic status, variables that seemed to account for the lower level of involvement of families with dually diagnosed children.

Conclusions: Greater distance between the family home and the residential treatment center and low socioeconomic status greatly limit a family's accessibility for involvement with children in out-of-home placements. These obstacles are more likely to occur in families of dually diagnosed children. (Journal abstract)

Bulger, M.W., Wandersman, A. & Goldman, C.R. (1993). Burdens and gratifications of caregiving: Appraisal of parental care of adults with schizophrenia. *American Journal of Orthopsychiatry, 63*(2), 255-265.

Key Words: caregiving, schizophrenia, adults

The caregiving experiences of 60 parents of adults with schizophrenia were investigated for the presence of gratification; the role of the interpersonal caregiver-child relationship; and the effects of burden, gratification, conflict, and intimacy. Results indicate that relationships, as measured by intimacy and conflict, were more highly associated with burden and gratification than were severity of schizophrenic symptoms or degree of caregiving involvement. Implications for therapeutic interventions are discussed. (Journal abstract)

Donnelan, A. & Mirenda, P. (1984). Issues related to professional involvement with families of individuals with autism and other severe handicaps. *The Journal of the Association for Persons with Severe Handicaps (TASH), 9*(1), 16-24.

Key Words: autism, parent/professional collaboration, professional guidelines

The combination of social, cognitive, and communicative deficits associated with autism has contributed to a unique and complex relationship between parents and professionals who serve these individuals. This relationship has changed over time from one in which parents were blamed for their children's autism to the present situation in which the emphasis is on a parent-professional partnership.

This paper addresses some of the roots of non-productive parent-professional interaction related to individuals with autism and suggests some standards which might lead to more fruitful and positive relationships. (Journal abstract)

***Dunst, C., Trivette, C. & Cross, A. (1986). Mediating influences of social support: Personal, family, and child outcomes. *American Journal of Mental Deficiency, 90*(4), 402-417.**

Key Words: availability of support, family functioning, stress, coping strategies

The mediating influences of social support were examined in a study of 137 parents of mentally retarded, physically impaired, and developmentally at-risk children. Social system theory was used as a conceptual framework for assessing the effects of social support on personal well-being, parental attitudes toward their child, family integrity, parental perceptions of child functioning, parent-child play opportunities, and child behavior and development. A series of hierarchical multiple regression analyses by sets, controlling for family SES and income, child sex and age, and child developmental quotient and diagnosis showed that both satisfaction with support and number of sources of support had main and/or interactive effects in all sets of outcome measures. More supportive social networks were associated with better personal well-being, more positive attitudes, and more positive influences on parent-child play opportunities and child behavior and development. Findings were discussed in terms of both methodological and conceptual contributions to understanding the broad-based influences of social support. (Journal abstract)

Ellis, J.B. (1989). Grieving for the loss of the perfect child: Parents of children with handicaps. *Child and Adolescent Social Work, 6*(4), 259-270.

Key Words: grieving, children with special needs, families

Family reaction to the diagnosis of a child with a handicap marks the occurrence of a family crisis. The loss experienced by the family at the birth of a handicapped child is explored within a framework for grieving. A holistic model for the grieving process, which is based on a view that grieving has important biological, intellectual, emotional, behavioral and spiritual aspects is presented. Examples from clinical cases are offered to illustrate this process. Implications are provided for better understanding and facilitating of the grief process for both the family and the helping professional. (Journal abstract)

***Friedrich, W.N., Wilturner, L.T. & Cohen, D.S. (1985). Coping resources and parenting mentally retarded children. *American Journal of Mental Deficiency, 90*(2), 130-139.**

Key Words: coping strategies, developmental disabilities, marital satisfaction

The author describes a study of coping in mothers of children with developmental disabilities. The relative contributions of four types of resources to overall coping are compared. The four resource categories are: (1) utilitarian resources (e.g., socioeconomic status, money, available community programs and agencies); (2) health/energy/morale (e.g., depression, preexisting physical problems, psychopathology); (3) social networks (e.g., close positive interpersonal relationships); and (4) general and specific beliefs (e.g., self-efficacy, existential belief systems). In the first assessment, 140 mothers were involved; a follow-up assessment was performed 10 months later with 104 mothers. Regression analysis revealed all except utilitarian resources were significant contributors to overall coping.

Gallagher, J., Beckman, P. & Cross, A. (1983). Families of handicapped children: Sources of stress and its amelioration. *Exceptional Children, 50*(1), 10-19.

Key Words: needs assessment, family functioning, informal support systems

This literature review focuses on the stresses families experience and the support factors needed to help them cope with their handicapped children. Stress often appears to increase with the age of the handicapped child, and it is also based on the daily care-giving demands of the child. Other general factors affecting stress are low family income, divorce, separation, and so forth. The father often plays a limited role in these families even when present. Both formal and informal social support networks are important to these families, often more so than professional support, which has been uneven. Families need to be treated as having individual needs that require individual solutions, even as their handicapped children. Investigators and practitioners are encouraged to continue their focus on the family as a legitimate unit of study and treatment. (Journal abstract)

Goldfarb, L., Brotherson, M.J., Summers, J.A. & Turnbull, A.P. (1986). Defining the problem. In *Meeting the Challenge of Disability or Chronic Illness--A Family Guide*, pp. 101-121. Baltimore: Paul H. Brookes.

Key Words: needs assessment, stress, coping strategies

This chapter is part of a book which includes an examination of the family problem-solving process in response to a disability or chronic illness. This information is designed to help family members use and strengthen their own resources and apply them to specific problems. The authors suggest ways for families to identify and address unmet needs which have contributed to family and personal difficulties. The authors affirm the right and responsibility of family members to express needs, resolve problems and reduce negative consequences.

Strategies are offered for expressing needs, responding constructively, defining problems, and separating feelings from actions. Guidelines are also presented for distinguishing disability-related from nondisability-related issues. Finally, coping strategies are presented which involve defining the specific problem areas the family is able to control and establishing priorities for addressing those areas. For each aspect of the problem solving process, helpful exercises are included for individual and family use.

Hatfield, A. B. (1987). Social support and family coping. In Hatfield, A. B. & Lefley, H. P. (Eds.), *Families of the Mentally Ill: Coping and Adaptation*, pp. 191-207. New York: Guilford Press.

Key Words: social support, community, friendship, stress reduction

Hatfield discusses the importance of a social support network to help families cope with the stress of caring for someone with a mental or emotional disorder. In this chapter, social support is described as individual attachments, community involvement with others with similar life circumstances, and friendship and loyalty. Supports can be emotional, material (i.e. money, goods), and practical (i.e. baby sitting, giving advice). The author describes research related to social support networks and stress reduction, which includes implications for practitioners. This chapter contains a discussion of the self-help and support movement with an emphasis on the National Alliance for the Mentally Ill.

Iris, M.S. (1988). The parent/professional relationship: Complex connections, intricate bonds. *Family Resource Coalition Report*, 7(2), 9.

Key Words: parent/professional collaboration, service planning

The author is the mother of two sons with disabilities, one who is ten and the other is six. She describes the challenges of negotiating relationships with professionals who become involved with her family because of her sons' disabilities. A significant problem has been the limited perspective of professionals who view children in isolation from their family. The author describes her task as assuring that all family members receive needed attention, not just the child with a disability. Her desire is to work with professionals as a team in developing long-term, comprehensive plans for her sons' care. She notes that many professionals find this difficult and focus only on their particular areas of specialty and expertise.

In conclusion, the author states that working with her children is an opportunity and gift for the professional, in offering a chance to share the life of the child and family. Her family has developed successful relationships with professionals who have the courage to work closely with children and parents, the ability to respond to their unique needs and lifestyle, and to incorporate the family's choices into the professional's own goals.

Karp, N. (1993). Collaboration with families: From myth to reality. *The Journal of Emotional and Behavioral Problems, 1*(4), 21-23.

Key Words: collaboration

Speaking for families of children with special needs, Naomi Karp calls for authentic family-professional collaboration which will develop new visions for children and new expectations of schools and agencies. Families want to be supported rather than supplanted by professionals. If collaboration is to be more than rhetoric, both parties must recognize their rights and responsibilities in relationships of mutual respect. (Journal abstract)

Lieberman, F. (1989). Clients of patients: Families of children with developmental disabilities. *Child and Adolescent Social Work, 6*(4), 253-257.

Key Words: families, children, developmental disabilities

"Because of the multiple needs of children with developmental disabilities and the dearth of resources, the myriad of skilled professionals who are needed to care for these children tend to focus on the disabled child's problems; in the process, the needs of families are neglected. Yet, because of the importance of families to children, this really results in neglect of the child's most important resource. This issue of the Child & Adolescent Social Work Journal is devoted to that resource, the families of the children." (Author's introduction)

The author also discusses the importance of starting where the client is, having a client orientation rather than a patient orientation, and recognizing self-determination as an important value in social work. Two case examples are provided for illustration.

Lipsky, D. (1985). A parental perspective on stress and coping. *American Journal of Orthopsychiatry, 55*(4), 614-617.

Key Words: parent perspective, research, stress, coping strategies, availability of support, spina bifida

Both as a social science teacher and as a parent of a teenager with a neural tube defect (spina bifida), I have come to understand the pervasiveness of professional prejudice towards parents and professional misconceptions surrounding the stress parents face in caring for their disabled children. To increase the level of care of the disabled, it is essential that parents and professionals function as a cohesive team. If they are to work more effectively together, both must understand and seek to correct the often unrealistic viewpoint and negative assumptions concerning family stress and coping. (Selections from author's introduction)

The author cites examples of professionals' negative views of parents which are reflected in the research literature about families of children with disabilities. She discusses the limitations of this literature: (1) evidence of family stress based on research which has serious methodological flaws; (2) most studies were conducted before the advent of developments such as normalization and community-based care; (3) the focus of the research is on psychological factors and the role of the professional is inflated; and, (4) most studies only describe the negative aspects of stress and ignore interventions for reducing stress and supporting constructive coping. The author concludes that stress "...is most often not a factor of psychological dysfunction but, rather, the absence of a sympathetic social or economic support system."

May, J. (1988). Special needs children, special needs fathers. ***Family Resource Coalition Report, 7*****(2), 10.**

Key Words: parent perspective, parent/professional collaboration, guidelines, policy, fathers

The author discusses redefinition of self that occurs on becoming the father of a child with a disability. The author describes the trial for fathers in coming to terms with their dreams, fears, grief, and anger and their wish to be strong in the face of challenges.

Specific suggestions are offered for treatment professionals and program developers to enable fathers of children with disabilities to explore their feelings in a supportive setting. The author suggests that programs encourage fathers to be resources for each other. The purpose of treatment is to "facilitate men dealing with their pain as well as sharing the love and joy they have for their special kids."

McGarry, B. (1994). Parent's Online. ***Exceptional Parent, 24*****(6), 27-44.**

Key Words: social support, computers, telecommunications, on-line bulletin boards, information access

The author describes the use of computer online services by family members of persons with disabilities in order to obtain support and information from other families and search a wide variety of electronic data bases. Steps involved in getting online are described and several case examples are presented of families who have obtained relevant information and developed social support networks via computer. Brief explanations are provided on use of the Internet and online services including America Online, Compuserve, Delphi, eWorld, Genie, and Prodigy. Disability-related electronic bulletin board and mailing lists are also included.

"A few months ago, looking ahead to this special, telecommunications theme issue, and hoping to put a 'human face' on the technology, I set out on the 'information superhighway' looking for parents of children with disabilities. I got online and posted a few public invitations for parents to share their experiences with readers of Exceptional Parent. To say simply that the response amazed me would be an understatement. The sheer numbers took me by surprise--more than 300 pieces of electronic mail ("e-mail") flooded my online mailbox. I was even less prepared for the incredible power and emotion of the stories these letters told...or for the words parents used to describe others they knew only through printed text on a computer screen--words like 'close friends', 'family', and 'community'." (Author's introduction)

Mittler, P., Mittler, H. & McConachie, H. (1987). Working together: Guidelines for partnership between professionals and parents of children and young people with disabilities. In Lipsky, D. (Ed.), pp. 15-35. *Family Supports for Families with a Disabled Member.* New York: International Exchange of Experts and Information on Rehabilitation.

Key Words: parent/professional collaboration, parent perspective, guidelines

The authors describe the process of building a genuine partnership between children and their families and between families and professionals. The authors discuss several key features of relationships between parents and professionals: (1) mutual respect; (2) agreement on a common purpose; (3) joint decisions; (4) sharing feelings; and (5) flexibility. Obstacles to collaboration are outlined in detail, from both parent and professional perspectives. Practical suggestions are offered for improving working relationships between parents and professionals, which is the first major step toward building partnerships.

The authors describe a partnership in these terms: "In a true partnership, each person acquires an understanding of both the strengths and limitations of the other. Both parents and professionals are now beginning to understand how much they have to learn from one another and how much the progress of the child depends on their ability to work together in an atmosphere of trust and respect. This can only be created on the basis of a working knowledge of what each side can and cannot be expected to offer. This process requires time and understanding."

***Palfrey, J., Walker, D., Butler, J. & Singer, J. (1989). Patterns of response in families of chronically disabled children: An assessment in five metropolitan school districts. *American Journal of Orthopsychiatry, 59*(1), 94-104.**

Key Words: research, special education, parent perspective, stress, coping strategies, parent/professional collaboration

The authors present the results of a survey of parents of special education students regarding their employment, housing, friendships and needs for social support. The survey also explored the family's involvement in their child's special education program. The levels of stress reported by parents varied significantly according to the child's type of disability and the mother's level of education. Family involvement in the Individualized Education Plan (IEP) process also varied according to the parents' level of education.

The authors describe clinically important differences in family perceptions and coping mechanisms. Development of community programs must consider the need for child care and respite care and establish a commitment to participation of low-income parents in the IEP process.

***Quine, L. & Pahl, J. (1985). Examining the causes of stress in families with severely mentally handicapped children. *British Journal of Social Work, 15*, 501-517.**

Key Words: stress, families, behavioral disorder

Though it is recognized that the presence of a mentally handicapped child may be a source of stress for a family, less is known about precisely which impairments are particularly stressful. This question was investigated in a study of 200 families with severely mentally handicapped children living in two health districts in South East England. Interviews were carried out with the people responsible for the day-to-day care of the children and stress was measured by means of the Malaise Inventory. The results suggested that the highest levels of stress were associated with the presence of a child with behaviour disorders or with multiple impairments; the stressfulness of these conditions was exacerbated by adversity. A regression analysis showed that the factors causing most stress in (caregivers) were, in order of importance: behaviour problems in the child, night-time disturbance, social isolation, adversity in the family, multiplicity of impairments, difficulty in settling the child at night, problems with the child's health, problems with the child's appearance, and money worries. The article ends with recommendations for the development of services aimed at reducing stress in families with mentally handicapped children. (Journal abstract)

Schilling, R.F. & Schinke, S.P. (1984). Personal coping and social support for parents of handicapped children. *Children and Youth Services Review, 6*, 195-206.

Key Words: coping strategies, social support

Human services workers have long recognized that parents of handicapped children experience inordinate stresses. In recent years investigators have examined how such families deal with stress. This paper discusses stress in families of developmentally disabled children and how parents of special needs children draw on personal and social coping strategies to manage daily challenges. An overview of existing research is followed by a prescription for research on stress, personal coping, and social support. The authors call for prevention strategies to prevent stress-related maltreatment of special needs children. (Journal abstract)

***Singer, G.H.S., Irvin, L.K. & Hawkins, N. (1988). Stress management training for parents of children with severe handicaps. *Mental Retardation, 26*(5), 269-277.**

Key Words: stress, training, families

The use of coping skills training was examined as a way to treat demoralization of parents with children who have severe handicaps. Thirty-six parents of school-aged children with severe handicaps were randomly assigned to a treatment group and a waiting list control group. The intervention consisted of a series of eight classes on self-monitoring, progressive muscle relaxation, use of relaxation as an active coping skill, and cognitive reframing. The treatment group improved significantly on measures of depression and anxiety. Social validation and descriptive data were also presented. Results suggest that a psychoeducational approach to coping skills offered in the context of a support group can be an effective means of assisting parents. (Journal abstract)

***Stallard, P. & Lenton, S. (1992). How satisfied are parents of pre-school children who have special needs with the services they have received? A consumer survey. *Child Care, Health and Development, 18*, 197-205.**

Key Words: parent satisfaction, preschool, children with special needs, survey

The parents of 41 pre-school children with special needs volunteered to participate in a consumer survey to ascertain their satisfaction with the services they had received and how these could be improved. The survey produced an overall high level of satisfaction, although parents felt they had not received as much information as they wanted on their child's condition (29%), available help for their family (44%), financial benefits (61%), or information about their child's future (61%). Families also felt that they had not received enough family support (43%), and that professionals regularly did not understand their concerns (32%). Ways in which these issues could be addressed are discussed, along with more general issues of such consumer satisfaction surveys. (Journal abstract)

Turnbull, A. P. & Turnbull, H.R. (1986). Family support: Helping families cope. In Turnbull, A.P. & Rutherford, H. (Eds.). *Families, Professionals and Exceptionality*, pp. 304-323. Columbus OH: Merrill.

Key Words: coping strategies, parent/professional collaboration

The authors describe internal and external coping strategies used by families, using examples of the ways in which schools can provide family support. Internal strategies involve problem-solving and changing perceptions and responses to stressful situations. External strategies refer to mobilizing resources to address needs and problems. The authors discuss the problem-solving process and emphasize the use of positive redefinition in alleviating stress and effectively meeting needs. Professionals are urged to accept parents' responses, timing, and preferred coping strategies as part of the process of adapting to their child's disability. The authors describe the value of respite care in alleviating stress and eventually preventing out of home placement. However, they indicate that parents may need extra encouragement to take time from these responsibilities and overcome the guilt from having someone else care for their child.

Research findings are reviewed with regard to the characteristics of effective support systems. The authors present alternatives for social support, such as support groups, mentorship programs, and outreach to members of the extended family. The authors caution that professional support may contribute to family stress unless it is offered in a sensitive, nonjudgmental, and respectful manner. In the authors' view, the most effective professional support is in helping the family to negotiate and coordinate the complex, varied services available to their child.

***Wikler, L., Wasow, M., & Hatfield, E. (1983). Seeking strengths in families of developmentally delayed children. *Social Work, 28*(4), 313-315.**

Key Words: strengths, parent/professional collaboration, sorrow, social workers, developmental disability

The authors found that most social workers in their study were aware that many families of developmentally disabled children experience chronic sorrow, defined as "sadness that did not disappear over time." However, social workers greatly underestimated the extent to which families felt that they had been made much stronger

by the experience of caring for a mentally retarded child. Social workers also underestimated the extent to which parents wished to be encouraged to be strong and to cope.

Several recommendations are presented in order to help workers determine and emphasize family strengths: (1) workers should be aware that growth and benefits may occur from having an exceptional child as well as stress and grief; (2) in their first meetings with the family, workers should ask parents about unique traits their children have which they appreciate; (3) family strengths should be assessed by asking parents for stories of successful family coping; and (4) workers should link parents with other parents who also have a child with developmental disabilities and have been successful in coping.

Woolley, H. (1991). Cornerstone careers for family support.** ***Nursing Times, ***87*****(43), 56.**

Key Words: case management, progressive degenerative disease

The author briefly describes a study on the role of case manager for families of children who are dying of a degenerative disease. A questionnaire and interview were used to assess qualities of professionals and services which parents found most helpful. Parents were also asked whom they thought was their "central coordinating" or "cornerstone" caregiver. Several qualities of professionals were found to contribute to a helpful, "cornerstone" relationship with families. Among these qualities are: (1) personality; (2) availability; (3) ability of professionals to accept parents' distress; (4) knowledge of resources; and (5) permanence.

SERVICE SYSTEM AND POLICY

Aldgate, J., Pratt, R. & Duggan, M. (1989). Using care away from home to prevent family breakdown. *Adoption & Fostering, 13*(2), 21-37.

Key Words: England, respite care, prevention

The author addresses a section of the Children Bill of 1989 that would widen family support services for families under stress by providing respite services arranged in partnership with parents. Attempts to implement the provisions of the Children Bill at the county level are reviewed. The six primary aims of the implementation scheme were: (1) to prevent family breakdown and full-time admission to care; (2) to preserve and enhance the relationship between parents and children; (3) to enhance the competence of parents; (4) to improve the behavior of children, where necessary; (5) to widen children's perception and experience of life in families, without damaging their attachment to their birth parents; and (6) to improve the quality of life of families living in continuing poverty. Specific roles of service providers, caregivers, and parents are discussed along with practical recommendations for implementation.

American Orthopsychiatric Association (1994). *Report of the Task Force on Head Start and Mental Health*. New York: The American Orthopsychiatric Association, Inc.

Key Words: Head Start, mental health, recommendations

A task force of the American Orthopsychiatric Association was organized in the fall of 1993 to recommend guidelines for strengthening the family support/mental health aspects of Head Start. The task force reviewed the current state of family support/mental health services at Head Start programs across the country listed the following findings: (1) family stresses among Head Start parents--ranging from substance abuse to violence and depression--are greater today than ever before; (2) Head Start staff report increasing numbers of children showing challenging disruptive behavior. Staff often experience stress and burnout, and feel a great need for more help as they address these mental health related issues; (3) mental health related issues are a low priority in the staffing, administrative structure, budgeting, training, and technical efforts of Head Start, both at program and national levels; (4) formal linkages between Head Start and other federal programs such as EPSDT or the Children's Community Mental Health Services Act are infrequent; and (5) new developments in the fields of family support and children's mental health have not been widely integrated into Head Start programs.

The task force outlined six recommendations for addressing the findings above: (1) Head Start should update performance standards and monitoring tools; (2) Head Start should increase training and technical assistance strategies focused on family support and mental health; (3) Head Start should develop strategies to expand staff with family support and mental health expertise at the program level as well as at the central and regional levels; (4) Head Start should provide incentives and opportunities to local programs to strengthen family support and mental health; (5) Head Start should encourage collaboration between Head Start and the larger family support/mental health community at the federal, state, and local levels; and (6) Head Start should increase the knowledge base about family support and mental health related services and outcomes to children and families, and the effectiveness of service delivery strategies.

Bocchino, C. (1990). Legislative Update: The Family Support Act: A potential for promoting the development of poor children. *Pediatric Nursing, 16*(5), 494-495.

Key Words: Family Support Act, poverty

The author discusses the purposes of the Family Support Act and its relationship to Aid to Families with Dependent Children (AFDC). The Children's Health Access and Prevention Act of 1990 (CHAP) and the White House Task Force report on Infant Mortality are also briefly discussed.

***Braddock, D., Hemp, R., Fujiura, G., Bachelder, L., & Mitchell, D. (1989). Third national study of public spending for mental retardation and developmental disabilities: An overview. In *The State of the States in Developmental Disabilities*. Baltimore: Brookes Publishing Company.**

Key Words: survey, quantitative assessment, state spending, developmental disabilities

This chapter is Part I of The State of the States in Developmental Disabilities, a book detailing the results of a 1988 quantitative assessment of state-federal political system commitments to persons with disabilities and their families. The study relied on indicators such as the magnitude of developmental disabilities (MR/DD) funds budgeted over time as a percentage of state wealth, the numbers of persons served in settings of various size, and the degree of public financial support for large population care facilities versus support for smaller and more individualized programs and services. Part I of the book contains an analytical overview, while Part II profiles service delivery systems in each of the 50 states. The profiles include 11 figures which demonstrate service trends in each state during 1977-88. Also included are client services data and technical notes.

Bradley, V.J. & Agosta, J.M. (1985). Keeping your child at home: The case for family support. *Exceptional Parent, 15*(7), 10-22.

Key Words: placement prevention, Family Subsidy Act, Michigan

This paper discusses the need for family support, the philosophical basis for family support, and barriers to providing family support. It includes results from a survey describing what types of family support programs exist in each state, and the strengths and weaknesses of each approach. The paper concludes with a brief but detailed description of the family support program and Family Subsidy Act in Michigan. (Abstract by Center for Human Policy)

***Caldwell, H.C., Greene, A.D. & Billingsley, A. (1994). Family support programs in Black churches. In Katan, S.L. & Weissbourd, B. (Eds.), *Putting Families First*, pp. 137-160. San Francisco: Jossey-Bass.**

Key Words: African American, churches, research

With the growing number of social problems facing African American families today, the viability of Black churches as family support systems is indeed an important topic. The nature of current family support programs sponsored by Black churches, and the

characteristics of these churches and their senior ministers, are discussed in this chapter. We begin by examining the historical social service role of Black churches in African American communities and how it has changed over time. We then present preliminary findings from our ongoing research on what contemporary Black churches are doing to assist families. We include a discussion of service gaps that these programs may not be addressing. Finally, we offer suggestions, based on our findings, for expanding the presence of Black churches in the family support movement. (From Chapter Introduction)

Center on Human Policy (1987). *Families for All Children*. Syracuse, NY: Division of Special Education and Rehabilitation, School of Education, Syracuse University

Key Words: family caregiving, developmental disability, program description, service planning, service delivery

The Center on Human Policy has studied services for children with severe disabilities for the past two years, and has become more committed to the idea that children belong with families -- that families whose children have severe disabilities should be supported in as many ways as they need, and that children who cannot stay with the families into which they are born deserve to live with other families. This issue develops this theme. We offer, first, a policy statement on families and their children, a statement that has been endorsed by many individuals, organizations, and states around the country. Other articles in this issue look at family support, taking a parent's perspective and a broad look at family support nationally. We present ways in which family supports are being provided in Wisconsin, Michigan, New York, and Montana.

Some children, no matter what supports are available, cannot remain with the families into which they were born. Should they be placed in group settings with other children with severe disabilities, or in temporary foster homes, where they are moved from home to home throughout their childhood? We present the concept of permanency planning, and describe the experience of one state that has committed itself to this concept. Michigan is developing its services so that all children with disabilities, no matter how severe, can live with families and experience consistent, enduring relationships with adults. (Excerpt from editor's note)

Cohen, S. (1988). Respite care. *Respite Care and Family Resource Coalition Report, 7*(2), 11.

Key Words: respite care, public policy

The author provides basic information on the need for respite care and describes some of the different forms it may take, including in-home care and out-of-home services, weekend camps, and specialized group homes. She sees current respite services as one of several components of a comprehensive system of family support services, often supported by state governments. Families who use respite care services express two major reservations: (1) availability of services is limited; and (2) quality or skills of respite care staff is lacking. The author concludes with brief suggestions for improvement of respite care policy at the federal level.

Cole, B.S., Pearl, L.F. & Welsch, M.J. (1989). Education of social workers for intervention with families of children with special needs. *Child and Adolescent Social Work, 6*(4), 327-338.

Key Words: education, social workers, intervention, Public Law 99-457

The passage of Public Law 99-457 is likely to increase involvement of social workers with families who have children with special needs, which accentuates the need for responsive, competency-based social work education. The authors suggest four areas of competency which should facilitate work which social workers perform with children with developmental delays and their families: (1) awareness of common conditions which cause delays in early development; (2) awareness of the impact which the identification of delays may have on the family unit; (3) awareness of community resources which may provide services to children and/or their families; and (4) awareness of the roles which a social worker can fulfill in assisting families with young children with developmental delays.

Cross, T. (1986). Drawing on cultural tradition in Indian child welfare practice. *Social Casework: The Journal of Contemporary Social Work, 67*(5), 283-289.

Key Words: Native American, history, indigenous support, legislation, cultural traditions, child welfare, program description

The author is director of the National Indian Child Welfare Institute and presents an overview of the history of child welfare with regard to Native American children. The impact of the Indian Child Welfare Act of 1978 is discussed in terms of enabling tribes to reassert their cultural traditions through developing and operating child welfare services and utilizing natural support systems. The author states that "...current Indian child welfare practices are rooted in the earliest history of the Indian people..." He describes the values and teachings of Native American parenting which have preserved the integrity of tribal society. The article concludes with examples of tribal programs, parent classes and group processes to help Native Americans explore their heritage, identity, values and current social issues.

Crutcher, D.M. (1991). Family support in the home: Home visiting and Public Law 99-457. *American Psychologist, 46*(2), 138-140.

Key Words: Public Law 99-457, Hawaii, parent-professional collaboration

The author provides her own parent perspective on issues discussed at the working conference, Family Support in the Home: Home Visiting Programs and Public Law (PL)99-457, which was held in Honolulu, Hawaii during February 1988. Although several conclusions reached at the conference are discussed, the author emphasizes elements of successful parent-professional collaboration. The author makes several suggestions about partnerships between parents and professionals, including: (1) professionals must understand that most parents are basically competent people who are raising all of their children the best way they know how; (2) professionals should offer encouragement to families, even though their training may caution against it; and (3) parents should be made to feel comfortable with the qualifications of a home visitor, but not overwhelmed by them.

Dean, C. (1993). Strengthening families: From "deficit" to "empowerment." *Journal of Emotional and Behavioral Problems, 2*(4), 8-11.

Key Words: empowerment, deficit, service delivery

Over the past decade, human-service providers and consumers of services have grown increasingly vocal that it is the system rather than families, that should be labeled "dysfunctional". Families seeking help with basic needs too often wend their way through a maze of paperwork, eligibility restrictions, and loss of privacy only to discover that the assistance they need is unavailable or offered in such a degrading way that they decide to do without it. Workers often feel frustrated with bureaucratic constraints and question whether the structure is working when they see generations of families repeating the same cycles of dependency and abuse. (Journal abstract)

The author contends that a shift must take place in the beliefs and attitudes held by clients, workers, and programs from a "deficit" to an "empowerment" orientation. Specific belief and attitude changes are described. New "empowerment" skills required by agency workers are also listed.

Deiner, P. (1987). Systems of care for disabled children and family members: New paradigms and alternatives. *Marriage and Family Review, 11*(1/2), 193-211.

Key Words: family caregiving, developmental stages, family functioning, stress, service planning

The author asserts that concerns and issues confronting families caring for children with disabilities are idiosyncratic to the specific disability and the child's level of functioning. She maintains that the family's capacity for caregiving varies over the time; therefore, the system of care should change with the family's needs. The differing needs of couples, families with young children, school age children, adolescents, and young adults are discussed. Additional concerns may arise for families in later life, as well as for families dealing with divorce, single-parenting, or remarriage. Rather than labeling families as "uncooperative", she urges professionals to recognize that services may not be congruent with the family's current situation.

Family Support and Resource Center. (1988). Family support program needs assessment and family plan. In Center for Human Policy, Resources for Family Support, Research and Training Center on Community Integration, Syracuse University, Syracuse, NY. Family Support and Resource Center, 521 N. Sherman Avenue, Madison, WI 53704.

Key Words: needs assessment, service planning, availability of support

A form, developed by The Center for Human Policy, elicits information of family support needs. The form includes suggested "routine information" to be gathered such as: (1) brief descriptions of family members, ages, and relationships; (2) family income and expenses; (3) entitlement and insurance policy information; and (4) work information. Background information questions assess: (1) where the family gets support (e.g. friends, relatives, professionals, services); (2) effects of children's' disabilities on other family members; (3) types and level of family support required; and (4) current level of family input and control over services. The form concludes with questions on: (1) the families expectations about keeping their child at home; (2)

assessment of additional family support needs; and (3) other relevant additional information.

Florian, V. (1987). Cultural and ethnic aspects of family support services for parents of a child with a disability. In Lipsky, D. (Ed.), *In-family Supports for Families with a Disabled Member.* New York: International Exchange of Experts and Information in Rehabilitation, World Rehabilitation Fund, Monograph Number 39, pp. 37-55.

Key Words: cultural traditions, needs assessment, availability of support, service delivery

Social scientists are beginning to recognize the importance of cross-cultural and cross-ethnic studies to expand theoretical and practical knowledge of family patterns, functions, and relationships. However, few studies have been conducted regarding the reactions of various ethnic groups to the disability of a family member or of cross-cultural implications for service. The author asserts "as long as the impact of ethnic and cultural factors influencing families are de-emphasized or neglected by policy makers and service providers, it can be assumed that the whole range of professional family support services will be limited in their effectiveness."

The author proposes that conditions for parents of children with disabilities can be better understood on two levels: (1) the psychosocial stages of parental reactions to the child with a disability; and (2) the impact of the child's condition on various areas of family life--financial, social, somatic and behavioral. Cultural and ethnic factors are discussed as determinants of reactions to a child with a disability, with specific examples from ethnic minorities in the US and in Arab and Jewish communities in Israel. Implications for service delivery are outlined in the context of the two levels described above.

Focal Point. (1988). Family support: Perspectives on the provision of family support services. *Focal Point*, 2(3).

Key Words: crisis, education, skills, respite care, family support events

This issue of *Focal Point* has an introduction by Madeleine Will, at that time, Assistant Secretary for Special Education and Rehabilitative Services, U.S. Department of Education. A feature article presents a developmental model for understanding the experience of many families with children who have serious emotional disorders. The model has five components: 1) crisis; 2) information/education; 3) skills development; 4) emotional support; and 5) task-oriented activities.

A second article briefly describes several respite care models, including: 1) homemaker services; 2) sitter/companion services; 3) parent trainer services; 4) care in provider's home; 5) foster care or licensed family care; 6) group day care; 7) residential respite care; 8) residential treatment respite services; 9) crisis nurseries and emergency respite care facilities; and 10) generic community services as respite care. The remaining sections include a statement of family support principles, family support perspectives submitted by parents and professionals, and a bulletin board that contains brief descriptions of available family support resources, programs, and upcoming events.

***Frankel, H. (1988). Family-centered, home-based services in child protection: A review of the research. *Social Service Review*, March, 137-157.**

Key Words: research, child welfare, in-home services

The permanency planning movement, with its renewed interest on placement prevention and family reunification, has created increased interest in family-centered, home-based services as a child protection modality. Although its advocates claim that the effectiveness of these services is well established, an examination of the available research leads to a far less conclusive result. This article outlines the development of family-centered, home-based services and discusses their application to child protection. Using findings from established programs and demonstration projects, the research on family-centered, home-based child protection services is critically reviewed, and suggestions for further study are proposed. (Journal abstract)

***Fraser, M. & Haapala, D. (1988). Home-based family treatment: A quantitative-qualitative assessment. *Journal of Applied Social Sciences, 12*(1), 1-23.**

Key Words: evaluation, in-home services, counseling, basic assistance, stress

The authors of this article identify key elements of home-based family therapy designed to prevent out-of-home placement. The researchers surveyed mothers, children and therapists who had participated in the Homebuilders Project, which was offered as a final alternative to out-of-home placement.

The survey group included 41 families referred to a state social services office for child maltreatment, severe psychiatric impairment, chronic disruptive behavior or other family difficulties. Seventeen therapists served these families and were included in the research study. The study combines both process and outcome evaluation designs, which the authors contend to be critical in demonstrating program effectiveness. Eight dimensions of treatment are defined and respondents indicated the value of each activity within each of the dimensions.

Results of the study suggest a need for more precise definitions of activities to identify those considered of greater therapeutic value. The authors note the qualitative differences between performing activities in the context of a therapeutic relationship or within a family, friendship, or community. The survey results also indicate that concrete assistance resulted in more successful outcomes when incorporated into treatment.

Finally, the authors state that families need to be free from economic and social crises to be able to establish a therapeutic alliance. A review and careful assessment of family stressors is recommended before initiating treatment.

BEST COPY AVAILABLE

Freud, E. (1989). ***Family Support Programs for Families who have Children with Severe Emotional, Behavioral or Mental Disabilities: The State of the Art.*** **Monograph available from the Human Services Research Institute, 2336 Massachusetts Avenue, Cambridge, Massachusetts 02140, (617) 876-0426.**

Key Words: emotional disorder, behavioral disorder, family caregiving, parent training, advocacy, respite care, basic assistance

This monograph was written as part of a three year project funded by the National Institute of Disability and Rehabilitation Research. The intent of this project is to identify and explore various approaches to supporting families who care for a child with a serious illness or severe disability at home. The purpose of this monograph is to profile model programs and discuss the direction of the most progressive thinking about family support programs for those families who have children with emotional, behavioral or mental disabilities. (Author's introduction)

Concepts in this monograph were developed, in part, as an outcome of a family support working group at the Next Steps Conference held in Washington, D.C. in December, 1988. The intent of the conference was to establish a national family agenda for families with children who have emotional or behavioral disabilities. The family support working group identified essential components of support necessary to enable families to care for their children at home. The author describes these components, which include: 1) self-help; 2) advocacy; 3) parent education; 4) respite care; 5) family-centered case management; and 6) cash assistance. Using these components, the author profiles two types of family support programs: (1) programs which systematically coordinate all or most of the components; and (2) programs which coordinate a cluster of components in a particularly innovative way. Program profiles include comprehensive program descriptions, service linkages, funding and referral sources, and development strategies. A contact list is attached for readers interested in direct information from program sources.

Friesen, B. J. & Koroloff, N. M. (1990). Family centered services: Implications for mental health administration and research. ***The Journal of Mental Health Administration, 17*****(1), 13-25.**

Key Words: mental health, administration, public policy

Efforts to move the system of care for children with serious emotional disorders toward community-based alternatives has prompted a growing recognition of the need for supportive services for families. This article examines the shifts in policy and administrative practice that are needed in order to move toward a family-centered system of care. Proactive administrative support is particularly important in this system shift. Four important barriers to a family-centered system of care are examined: (1) efforts have tended to focus on the child as the unit of services, rather than on the family; (2) efforts have tended to focus primarily on mental health services, rather than considering the full range of services needed by the child and family; (3) efforts have tended to emphasize formal services, often ignoring the support provided by informal networks; and (4) the resources and expertise of parents and other family members have not been used. New roles for parents--which involve working with administrators and providers as partners--are described, and implications for mental health administrators and researchers are discussed. (Journal abstract)

Friesen, B.J., Griesbach, J., Jacobs, J.H., Katz-Leavy, J. & Olson, D. (1988). Caring for severely emotionally disturbed children and youth: Improving services for families. *Children Today, 17*(4), 18-22.

Key Words: emotional disorder, service delivery, Wisconsin

"This article describes how parents and professionals are working together to ensure that goals related to family support are translated into necessary policies, programs and services within the system of care for children and youth with serious emotional disorders. As an example of such efforts, a parent organizing project in Wisconsin is featured." (From the authors' introduction)

The authors provide a short history of parent involvement, a brief description of types of family support services in general, a synopsis of state and national efforts related to family support, and an account of the development of Wisconsin Family Ties (WFT), a statewide parent/family organization dedicated to family support and advocacy.

Hartman, A. F., Radin, M. B., & McConnell, B. (1992). Parent-to-parent support: A critical component of health care services for families. *Issues in Comprehensive Pediatric Nursing, 15,* 55-67.

Key Words: support groups, chronic illness, parent-to-parent support

Families of children with chronic medical conditions or disabilities face many unique difficulties. It is often necessary for them to assimilate technical medical information and participate in important decisions regarding their children's care before they have had time to adjust to their children's condition. Health care providers are not always available to help parents learn how to function in their dramatically changed roles. To adjust to their new parenting roles and work through feelings of confusion, denial, anxiety, guilt, anger, and depression, parents of children with special health care needs need opportunities to fully vent feelings, and to experience the grieving processes in their own way and at their own pace, in a nonthreatening, nonjudgmental environment. An informal support network is a powerful tool for accomplishing these tasks, for teaching day-to-day coping skills, and for supporting the establishment of new value systems that incorporate families' unique needs. The literature on family support documents ways in which parents of children with special health care needs are particularly qualified to help each other. This article briefly describes the philosophy of parent-to-parent support, its unique contributions in the health care setting, and the ways that health care providers can assist in creating an environment in which parents and professionals can work together more effectively. (Journal abstract)

Herman, S.E. & Hazel, K.L. (1991). Evaluation of family support services: Changes in availability and accessibility. *Mental Retardation, 29*(6), 351-357.

Key Words: evaluation, availability of support, accessibility, Michigan, public policy

Changes in availability and accessibility of family support services were studied by surveying county mental health authorities in Michigan before and after the implementation of new policy on and funding for such programs. An overall increase in the availability of family support services was found. Access to services as measured by length of time families waited for services remained unchanged following the increase in funds. Policy and funding implications of the study were discussed. (Journal abstract)

Hess, P. M. (1993). Supporting foster families in their support of families. *Journal of Emotional and Behavioral Problems, 2*(4), 24-27.

Key Words: foster care, foster families, reunification

The author describes a number of responsibilities that foster parents have in responding to the needs of foster children as well as the families from which they come. Foster parents interact with a full spectrum of community agencies and professionals on behalf of foster children and their families. Because of their unique position as 24-hour service providers for children and families, foster parents can make a valuable contribution as partners on the child/family service team. Several issues, if properly addressed, will facilitate this partnership and provide proper support for foster families in their roles. These include: (1) respect for foster parents' knowledge and skills and recognition of the unique dilemmas inherent in their role, (2) role negotiation and delineation; (3) information exchange; (4) The involvement of foster parents in making decisions; and (5) adequacy of family support resources for foster families.

Human Services Research Institute (nd). Expecting excellence in family support . Salem, OR: Human Services Research Institute.

Key Words: goals, program assessment, program evaluation

This brochure briefly describes essential goals and practices of successful family support and includes a rating form for program assessment. The rating form provides a format for measuring program quality on several dimensions: 1) vision; 2) family control; 3) planning for support; 4) receiving supports; 5) using community resources; 6) the extent to which services are family driven; 7) ease of service use; 8) flexibility; 9) policy making; 10) provision of supports; 11) organizational structure; and 12) program outcomes.

Institute on Community Integration (1990). *Impact*. Minneapolis, MN: Research and Training Center on Community Living and Institute on Community Integration, University of Minnesota.

Key Words: personal stories, programs, periodicals

Family support is a term that is defined and utilized by each family in their own individualized way as they strive to reach beyond survival to the vision of life they wish to realize for their family and for their members with disabilities. This issue of IMPACT shares personal stories about families who are finding the support and empowerment they need from a variety of sources. It also highlights national, state, and local programs that are addressing the issues of family support. It is our hope that this collection of articles will reveal both the challenges and possibilities of family support, offering encouragement to those seeking to meet the needs of their own or others' families. (Excerpt from editor's message)

This issue includes the following sections on family support: 1) Government Programs; 2) Policy, Law, and Power; 3) Families as Case Managers; 4) Technology; 5) Respite; 6) In-Home Support Issues; 7) Knowledge as Power; 8) Influencing Policy; and 9) Personal Planning.

Knoll, J. & Bedford, S. (1989). Respite services: A national survey of parents' experience. ***Exceptional Parent, 19*****(4), 34-43.**

Key Words: parent perspective, family caregiving, respite care, parent/professional collaboration, research

The authors summarize the results from a survey about respite care from readers of 50 states, the District of Columbia and Puerto Rico. Respondents were the child's primary caretakers, 85% of whom were mothers in two-parent homes. The average age of the child with a disability was 8.8 years. From the survey results, the authors state that current respite services do not embrace the concept of parent empowerment; however, parents want to retain control and have respite care providers be responsible to them.

Respondents reported that their daily needs have not been met by either respite or "generic" day care. The authors describe the public perception that respite is "an extraordinary resource made available to families." Conversely, the families surveyed perceive respite as "...a necessary and regular part of daily life." According to the survey, parents want to exercise control over respite services and to assume a substantial role in developing and redesigning a service system which is responsive to their family needs. A directory of state family support services is also provided.

Krauss, M. & Giele, J. (1987). Services to families during three stages of a handicapped person's life. ***Marriage and Family Review, 11*****(1/2), 213-229.**

Key Words: parent/professional collaboration, agency policy, developmental stages, service planning

The authors examine the relationship between the family and the public social service system in caring for individuals with a disability. The authors discuss the capacity of service systems to facilitate or impede the functioning of families. In their view, service systems tend to focus primarily on the individual with the disability and ignore the family and social context in which they live. Programs supporting families in delivering in-home care are often underfunded and of uncertain duration, while those providing out-of-home care predominate.

The authors recommend that services consider and address the needs and conditions of the whole family. Three stages are described in the life of the person with a disability; service needs and approaches are suggested for each stage. The stages are: (1) infancy and toddlerhood, when parents may first become involved in services provided to their child; (2) school-age childhood, when empowerment of parents in their child's education becomes important; and, (3) young adulthood, when parents become involved in planning for their child's independent living. The authors maintain that services at all life stages must meet three specific needs of families of children with disabilities: (1) information about the child's handicap; (2) advice about using the service system; and, 3) emotional support.

Leashore, B. R., McMurray, H. L. & Bailey, B. C. (1991). Reuniting and preserving African-American families. In Everett, J. E., Chipungu, S. S. & Leashore, B. R., *Child Welfare: An Africentric Perspective*, pp. 247-265. New Brunswick, NJ: Rutgers University Press.

Key Words: African American, community, resources, reunification

This chapter focuses on how resources within African-American communities can be used to support reunification of families when a child has been placed out of the home. The authors state, "Inadequate resources and supportive services continue to be barriers to family reunification and preservation, especially for families of color." A family support demonstration project, conducted in Washington D.C. using community-based resources to reunite families is described. An assessment conducted before the project began identified needed resources as housing, family counseling, drug treatment, day care, furniture, employment, financial assistance, and parent-skills training. The authors also describe the need to explore the use of extended family and fictive kin as resources for children and families. (Outcome data on the demonstration project are not presented.)

Loop, B. & Hitzing, W. (1980). Family resource services and support systems for families with handicapped children. ERIC Document 196254.

Key Words: public policy, history, service planning, service delivery, developmental disabilities

The monograph provides an historical overview of services for families of disabled children and considers strategies for increasing family support. The historical analysis traces factors influencing the lack of priority placed on family services and describes trends in family resource services. Advantages and drawbacks of the continuum and array approaches are considered. The array approach is seen to lead communities toward the development of a variety of services rather than continuums of different, segregated environments. Four critical components of such an array model are delineated: meaningful consumer involvement, generic agency development, legal framework, and training. The effects of the continuum approach on the development of temporary supports and respite care are examined. Recommendations for change are made for the program level as well as for the national policy level. (ERIC abstract)

Moroney, R. (1986). *Shared Responsibility: Families and Social Policy*. New York: Aldine De Gruyter.

Key Words: public policy, family caregiving, service planning, service delivery, developmental disabilities

The author discusses the relationship between the family and the state in caring for persons with special needs. He maintains that this responsibility is shared between family members and society and should be addressed through governmental means. In the author's view, the US government has not sufficiently supported families providing special care, so that these families must often bear an excessive burden. The author focuses specifically on the needs and conditions of families caring for the elderly and for children with developmental disabilities, demonstrating the lack of availability or accessibility of support services.

Values and trends contributing to current social policies and levels of service delivery are also discussed. The author notes the strong tendency for social service policies and practice to substitute rather than support families. This tendency has led to over reliance on institutional care and insufficient support to families for in-home services. The author recommends supports such as respite care and a special care allowance as provided in many Western European countries. He also urges changes in the role of professionals to include family members in the team serving and supporting the dependent individual.

Moroney, R.M. (1978). The family as a social service: Implications for policy and practice. *Child Welfare, 57*(4), 211-220.

Key Words: public policy, practice

The author discusses the shared responsibilities of the welfare state and the family in providing care for the handicapped. The author asserts that the family makes a significant contribution to caring which should be recognized, and public policy and local practice should be revised to reflect that recognition. At present, support for families in their caretaking roles receives low priority; higher priority is given to efforts on behalf of individuals who have no family or whose family performs little or no caretaking role. Training of social service professionals tends to focus on recognizing and ameliorating pathology, rather than prevention. Thus, professionals tend to structure their efforts and organizational goals toward attending to crises. Since many families caring for people with disabilities are not in an acute crisis, their needs are less likely to be recognized and met. New policy and practice should focus more on supporting the family in caring for its members with a disability instead of maintaining higher priority for efforts that focus solely on the individual and substitute or partially substitute for the family.

Moxley, D.P., Raider, M.C. & Cohen, S.N. (1989). Specifying and facilitating family involvement in services to persons with developmental disabilities. *Child and Adolescent Social Work, 6*(4), 301-312.

Key Words: family involvement, developmental disabilities

The authors present a framework for family involvement in services to persons with developmental disabilities. The framework incorporates four system levels: (1) the individual; (2) program/agency; (3) community; and (4) society. Five role opportunities for family members are also suggested: (1) treatment agent; (2) planner; (3) advocate; (4) evaluator; and (5) consultant/educator. A process for promoting family involvement is described, which includes: (1) contracting for involvement; (2) developing a support system for involvement; and (3) monitoring and evaluating involvement. (Edited journal abstract)

Olson, D. (1988). A developmental approach to family support: A conceptual framework. *Focal Point, 2*(3), Portland, OR: Research and Training Center on Family Support and Children's Mental Health.

Key Words: developmental stages, family caregiving, service planning, crisis intervention, emotional disorder

Families whose children have severe emotional disorders have many similarities. They are not, however, a homogeneous group: at any particular point in time families do not all have the same needs or desires. In taking steps to provide family support, it is critical to understand the developmental process many families with seriously emotionally disturbed children encounter. Once the process is understood, efforts addressing family needs can become more focused. A framework is presented here for understanding the developmental process and its importance to efforts supporting parents." (Author's introduction)

The author's framework consists of the following phases: (1) crisis; (2) information/education; (3) skills development; (4) emotional support; and, (5) task-oriented activities. Although presented and discussed separately, the author states that these phases are interrelated. The author also notes that the developmental process is not linear; for instance, a family may experience a number of "crises" and cycle through the process several times. Therefore, services should be designed to provide support, information, and skill development to stabilize each new crisis and enable parents to improve their ability to meet their child's needs. Over time, parents' effectiveness may be enhanced in meeting their child's needs and in changing the system.

Patterson, J.M. (1991). A family systems perspective for working with youth with disability. *Pediatrician, 18*, 129-141.

Key Words: chronic illness, disabilities, family systems, adolescence, parent/professional collaboration

In this paper, a family systems approach is advocated as an optimal model for managing the health care of youth with disabilities. The impact of the youth's disability on family functioning and, reciprocally, the impact of the family system on the course of the disability and the youth's development are reviewed. These two effects are viewed as mutually causal and thus call for a nonlinear approach to treatment -- one where both adolescent and family outcomes are simultaneously considered. The implications for pediatric practice of adopting a family system perspective in working with youth with disability is emphasized. (Journal abstract)

Petr, C.G. & Barney, D.D. (1993). Reasonable efforts for children with disabilities: The parents' perspective. *Social Work, 38*(3), 247-253.

Key Words: families, disabilities, content analysis

This article reports the results of a content analysis of focus group interviews of parents of children with developmental disabilities, emotional disorders, and technology-supported needs. Perspectives regarding special needs, crisis situations, and parent-professional relationships are discussed. Implications for policy and practice include targeting specific services, monitoring values of programs and staff, and minimizing system-induced crisis. (Journal abstract)

Pilisuk, M. & Parks, S.H. (1988). Caregiving: Where families need help. ***Social Work, 33*****(5), 436-440.**

Key Words: caregiving, public policy

Demographic and medical changes are turning numerous individuals into caregivers. The concept of caregiver burden is examined relative to the resources available for supporting family members who care for an ill or disabled member. An examination of the magnitude of the problem shows that there must be a national policy on caregiving and a shift in national priorities if the need is to be met. (Journal abstract)

Rapp, C. (1982). Effect of the availability of family support services on decisions about child placement. ***Social Work Research and Abstracts, 18*****(1), 21-27.**

Key Words: child welfare, research, availability of support, service delivery, staff training, agency policy, research

The author asserts that child welfare referrals for permanency planning often assume foster placement would be prevented if in-home support services were available. However, in a study of 542 child welfare workers in Illinois, the author found the availability of support services to have little influence on workers' placement decisions. Instead, workers frequently made placement decisions first and then determined the services available.

Factors other than availability of services affect placement decisions: worker ideology and attitude, caseload size, and organizational practices. The author concludes that changes in child welfare policies designed to maintain children in their homes are "at the mercy of decision-making by front-line workers." He calls for a functional approach that would identify parental responsibilities and match agency services to these child-caring tasks. He contends that family support services would serve as a realistic alternative to placement if this functional approach were utilized and training provided to workers to increase their awareness of alternatives.

Red Horse, J. (1980). American Indian elders: Unifiers of Indian families. ***Social Casework, 61*****(8), 490-493.**

Key Words: cultural competence, Native American, cultural traditions, indigenous support

The author describes the important role which elders play in giving strength and continuity to American Indian family life. He draws a contrast between American Indian traditions of family unity through the generations and the individualistic nuclear family systems prevalent in our society. The author explains, "Nuclear families program an increase in independence with an increase in age. Individuals have autonomous responsibility and strive for eventual retirement away from and uninvolvement in the mainstream affairs of their children's families. Elders in Indian extended families, however, assume mutual responsibility through interdependent responsibilities. Family obligation increases with increasing age." Among important traditional obligations which elders fulfill are providing discipline and spiritual guidance to younger generations. The author asserts that social service providers must consider this traditional integration of generations when designing and implementing programs. Otherwise, social programs may serve to weaken Indian families by isolating elders from children.

Roberts, R.N., Wasik, B.H., Casto, G. & Ramey, C.T. (1991). Family support in the home: Programs, policy, and social change. *American Psychologist, 46*(2), 131-137.

Key Words: policy, practice recommendations

The need for a coordinated national policy on family support in the home is discussed. First, the history of home visiting programs is reviewed. Then, recommendations for practice, training, and research in family support programs are presented. A discussion of the impact of new federal initiatives on family support programs and research demonstration efforts follows. (Journal abstract)

The authors discuss several issues and recommendations arising from the 1988 Conference on Family Support in the Home. The conference was attended by parents, practitioners, researchers, and policymakers. Recommendations for practice from the conference included: (1) shifting the focus of services from individuals to families; (2) recognizing that changes in one family member must be viewed as potentially affecting all family members; (3) supporting the family as collaborators, decision makers, and problem solvers; and (4) emphasizing the need to be sensitive to sociocultural diversity among families in terms of values and beliefs and to build on the strengths of each family.

Shoultz, B. (1988). *My Home, Not Theirs: Promising Approaches in Mental Health and Developmental Disabilities*. Syracuse, NY: Research and Training Center on Community Integration, Center on Human Policy, Syracuse University.

Key Words: mental health, developmental disabilities, placement prevention.

Serious problems exist with the residential services offered to people with psychiatric disabilities and to people with developmental disabilities. Children and adolescents with these disabilities are not supported to remain in their homes, and are typically moved into group or institutional care when they are placed out of the home. Adults are typically served within a continuum of services and are expected to move when they gain or lose skills or symptoms. The services that have traditionally been available are alien to the concept of "home" as a place of refuge or stability. Advocates for change are looking at programs and states which support people in individualized ways, which help each person to find and maintain a home. (Author's summary)

Shoultz, B. & Racino, J.A. (1988). Supporting people with medical and physical needs in the community. In *Resources on Supporting People with Extensive Health Needs in the Community*, pp. 1-19. Syracuse, NY: Research and Training Center on Community Integration, The Center on Human Policy, Syracuse University.

Key Words: community integration, health, physical disability

The Center on Human Policy has written a series of reports about agencies and services designed to meet the needs of people with severe disabilities. We have emphasized principles for community integration: (1) all people belong in the community; (2) people with severe disabilities should be integrated into typical neighborhoods, work environments, and community settings; (3) families should be supported to the degree necessary so their children can stay at home; (4) community living arrangements for adults should be family-scale and individualized; (5) a primary responsibility of

services should be the encouragement of relationships between people with severe disabilities and other people; and (6) parents and people with disabilities should be involved in the design, operation, and monitoring of services.

Based on this framework, we will highlight some of the best practices nationally in supporting children and adults with complex health needs in the community, and will examine selected issues raised in our review of the literature and our experience with existing service systems. (Authors' introduction)

The authors' discuss: (1) the meaning of "medically fragile" or "medical or health needs"; (2) assessment and services planning; (3) supporting the family; (4) permanency planning; (5) supporting adults in the community; (6) the role of technology; (7) lack of information exchange between the health care and developmental disabilities fields; and (8) enabling structures: training, funding, and other supports.

Shoultz, B. (1991). Looking at family support. ***Exceptional Parent*****, *21*(3), 30.**

Key Words: resources, principles

The author briefly discusses principles of family support services and provides suggestions for families who are working for the development of "comprehensive, accessible, and available family support services" in each state. A list of organizations which provide reports, articles, and other resources on family support is provided.

Singer, G. & Irvin, L. (1989).** ***Support for Caregiving Families: Enabling Positive Adaptation to Disability. **Baltimore: Paul H. Brookes.**

Key Words: family caregiving, parent/professional collaboration, stress, developmental stages, coping strategies, informal support, service planning, service delivery

This book is an overview of the family support movement and includes a discussion of the many forms and levels of support. According to the editors, "families have not been included actively in efforts to open the mainstream of society to citizens with disabilities, despite the fact that they are the primary and lifelong source of support for most persons with developmental disabilities."

Two major ideas from the study of families form the core of the book: family stress and the family life cycle. The six major sections of the volume are entitled: (1) An Orientation Toward Families and Support Services: Context, Structure and Goals; (2) Coping Skills and Informal Support; (3) Recurrent Needs for Formal Support; (4) Formal Support through the Family Life Cycle; (5) Treatment for Maladaptation; and (6) Evaluation and Policy.

Skarnulis, E. (1979). Support, not supplant, the natural home: Serving handicapped children and adults. In Maybanks, S. & Bryce, M. (Eds.), *Home-Based Services for Children and Families*, pp. 64-76. Springfield, IL: Charles C. Thomas.

Key Words: history, availability of support, respite care, in-home services, basic assistance

Each year, thousands of families are broken by unnecessary placements of handicapped children and adults into group homes, institutions, foster homes, and other residential facilities. The costs of such placements are high; family members are emotionally drained; society assumes a one million dollar debt for an individual's lifetime care; and the handicapped person, who is the pawn in the game, suffers the loss of loved ones as well as the loss of opportunities for normal development. (Author's introduction)

The author discusses the meaning and evolution of the principle of normalization and its place in the development of persons with mental retardation. He assails the assumption that persons need residential facilities simply because they are developmentally delayed. The author asserts that persons with mental retardation are not a homogeneous group. Some who have mild retardation are fully independent adults who are married, literate, and have well-paying jobs. The term "mentally retarded" may also be used to describe persons with profound retardation, or the medically fragile, or even a nonambulatory child. The author describes the needs of parents of persons with mental retardation. Instead of more diagnosis and assessment of their children, the author claims that parents "need generalists, not specialists." They need someone who can help by doing household chores, watching the children, performing home repairs, installing special equipment, helping with transportation, and providing financial assistance. The author concludes by discussing the meaning and application of the "least restrictive alternative."

***Slater, M.A., Bates, M. Eicher, L. & Wikler, L. (1986). Survey: Statewide family support programs. *Applied Research in Mental Retardation, 7*, 241-257.**

Key Words: survey, public policy, evaluation

Results of a survey of 23 state conducted family support programs are presented. Sixteen programs are legislatively mandated and the majority have a similar purpose: reduction of out-of-home placements. However, great variability exists on eligibility criteria, methods of program administration, amount of support, and types of services provided. Program evaluation data are reviewed indicating that cost benefits, decreased rates of out-of-home placement, and effects on family enhancement are primary concerns of these programs. Implications for future program development based upon normalization philosophy and stress-coping theories are presented. (Journal abstract)

Starkey, J. & Sarli, P. (1989). Respite and family support services: Responding to the need. *Child and Adolescent Social Work, 6*(4), 313-326.

Key Words: respite care, public policy

Increased focus on the needs of parents and guardians for structured opportunities for temporary relief from care of disabled persons has stimulated policy and implementation initiatives at the state government level on behalf of these families.

This article presents qualitative and quantitative data on the need for respite services not only in terms of relief, but as a positive, supportive force in the prevention of permanent placement outside the home. Current services are outlined and issues important to clinicians and managers working with such families are discussed. (Journal abstract)

Stehno, S. (1986). Family-centered child welfare services: New life for a historic idea. *Child Welfare, 65*(3), 231-239.

Key Words: public policy, history, child welfare, availability of support, parent/professional collaboration

The author asserts that the recent emphasis on permanency planning in child welfare demands that "...agencies reorient their entire focus from child placement to family support, asking nothing less of child welfare agencies than that they break with over 100 years of tradition." Clinical approaches which "blamed" parents for their children's difficulties and efforts to "save" children from their parents have impeded provision of family support and strengthened the emphasis on substitute care. However, the author considers several recent developments as creating a more supportive climate for the development of family-centered services. Social and economic changes have led to a need for support among a wide range of families, particularly due to the increased number of single parents and employed mothers.

The parent empowerment movement may also influence development of family support services. Although this is primarily a middle-class movement, it may lead to improved services for poor families and for those with special needs. New approaches are also described as contributing to a family-centered perspective, such as systems theory, home-based services, and recognition of the benefits of concrete services. The deinstitutionalization movement and enactment of Public Law 96-272, the Adoption Assistance and Child Welfare Act of 1980, have fostered development of family-centered support services by requiring agencies to prevent out-of-home placement. The author concludes that further development of family-centered services is needed and that the task is to assure that these services have a permanent and prominent place in child welfare services.

Stroul, B.A. & Friedman, R.M. (1988). Principles for a system of care. *Children Today, 17*(4), 11-15.

Key Words: system of care, values, principles

The authors describe two core values and a set of 10 principles for a system of care for children with severe emotional disorders and their families. The values and principles were developed through a project sponsored by the National Institute of Mental Health's Child and Adolescent Service System Program (CASSP). The two core values are: (1) the system must be driven by the needs of the child and his or her family; and (2) the system of care for emotionally disturbed children should be community based.

The 10 principles are: (1) children with serious emotional disorders should have access to a comprehensive array of services that address the child's physical, emotional, social, and educational needs; (2) children with serious emotional disorders should receive individualized services in accordance with the unique needs and potentials of each child and guided by an individualized service plan; (3) children with serious

emotional problems should receive services within the least restrictive, most normative environment that is clinically appropriate; (4) The families and surrogate families of children with emotional disorders should be full participants in all aspects of the planning and delivery of services; (5) children with emotional disorders should receive services that are integrated, with linkages between child care agencies and programs and mechanisms for planning, developing and coordinating services; (6) children with emotional problems should be provided with case management or similar mechanisms to ensure that multiple services are delivered in a coordinated and therapeutic manner and that they can move through the system of services in accordance with their changing needs; (7) early identification and intervention for children with emotional problems should be promoted by the system of care in order to enhance the likelihood of positive outcomes; (8) children with emotional disorders should be ensured smooth transitions to the adult service system as they reach maturity; (9) the rights of children with emotional disorders should be protected, and effective advocacy efforts for children and youth with emotional problems should be promoted; and (10) children with emotional disorders should receive services without regard to race, religion, national origin, sex, physical disability or other characteristics, and services should be sensitive and responsive to cultural differences and special needs.

United Cerebral Palsy Associations (1987 to present). *Family Support Bulletin*, United Cerebral Palsy Associations, Inc.

Key Words: periodical, public policy, recommendations, guidelines

The Family Support Bulletin is a periodical which provides: (1) public policy and legislative news and information on family support; (2) updates on family support developments in individual states; (3) news, editorials, and commentary on family support issues; (4) guidelines for family support programs; (5) brief research reviews; (6) descriptions of developments in education and assistive technologies; (7) a calendar of national and regional family support events; (8) a family support resource section; and (9) family support related individual stories.

Webb, S. (1990). Preventing reception into care: A literature review of respite care. *Adoption and Fostering, 14*(2), 21-26.

Key Words: respite care, literature review, England, Children Act

This article has been written as part of a study of the feasibility of providing respite care for children and families in a local authority social services department in England. The overall project was conceived firstly, as a way of examining how this type of provision might provide an alternative, in working with children and families, to reception into care, and avoid long-term family breakdown. Secondly, it was drawn up in anticipation of the Children Act, which reflects certain principles of prevention. (Journal introduction)

Whittaker, J.K. (1980). Family involvement in residential treatment: A support system for parents. In Maluccio, A.N. & Sinanoglu, P.A. (Eds.), *The Challenge of Partnership: Working with Parents of Children in Foster Care*. New York: Child Welfare League of America.

Key Words: residential treatment,

The residential treatment center, properly conceived and implemented, can provide a valuable supportive resource to biological parents, foster parents, and adoptive parents, and, in addition, has the potential for becoming a laboratory for developing a wide range of strategies for creative family involvement across the entire continuum of services to child and youth. In short, just as there is a need to reexamine biases toward biological parents, there must be rethinking on what potential there exists in all facets of the service continuum for providing support, encouragement, and competent professional help to parents and children in need. This is the overall message of this chapter. (From author's introduction)

The author discusses the transformation of residential treatment centers into child and resource centers and suggests the following steps take place: (1) all of us - professionals, parents, and concerned citizens - need to work harder to lessen the stigma of "placement," to see it as less an indicator that the "end of the road" has been reached and more as one step in the process of family helping; (2) we must accept that, while no single agency, practitioner, or service mode has all the answers, a tremendous amount of untapped wisdom exists in the practice community on building effective support systems for families; (3) on a smaller scale, we must assess the expertise that exists within individual programs on "parenting" and share information with staff and parents; (4) we must develop a helping perspective that includes the total ecology of the child's world, beginning with the family, but extending to the school, neighborhood, peer groups, church and other potentially supportive systems; and (5) we must ensure that, as far as possible, professionals who design programs to help parents have themselves had the experience of nurturing, caring for and helping a troubled or troublesome child through the major routines of daily living.

***Wiegerink, R. & Comfort, M. (1987). Parent involvement: Support for families of children with special needs. In Kagan, S., Powell, R., Weissbourd, B. & Zigler, E. (Eds.), *America's Family Support Programs: Perspectives and Prospects*, pp. 182-206. New Haven, CT: Yale University Press.**

Key Words: history, physical disability, emotional disorder, parent/professional collaboration, research, family involvement

The authors present a theoretical rationale for parent involvement in publicly funded services for young children with physical or emotional disabilities, criticisms of the parent involvement concept, a description of parent-involvement roles and activities, and a discussion of special needs of parents. Varied foci and activities of family support programs are explained in a detailed table, and research on the impact and effectiveness of several programs is reviewed. In addition, the authors describe the change in early intervention services over a 15 year period from a focus on the child, to a focus on the mother, and finally, to a family focus.

The authors conclude "practitioners will need training in family assessment, planning, and evaluation aimed at interdisciplinary intervention. Without question, parent involvement is already a fixed feature and family-focused services are the latest development in early intervention for handicapped children. Careful research, training,

and interagency collaboration will enable parents and professionals to match intervention services to the special needs of families with young handicapped children."

Wintersteen, R.T. & Young, L. (1988). Effective professional collaboration with family support groups. ***Psychosocial Rehabilitation Journal, 12*****(1), 19-31.**

Key Words: support groups, collaboration, mental health

Support groups for families of the mentally ill provide assistance for many people coping with the illness of a family member. Many groups have professional advisors who help them in various ways. Research and practice experience suggest that the roles that advisors play are different from the roles played by professionals in clinical group practice. Liaison must enhance the strength and vitality of groups. Based on research findings, guidelines for professional practice as a group advisor are presented. (Journal abstract)

FAMILY SUPPORT PROGRAMS AND SERVICES

Anglin, J. (1985/86). Developing education and support groups for parents of children in residential care. *Residential Group Care and Treatment, 3*(2), 15-27.

Key Words: residential treatment, aftercare, support groups, service planning, service delivery,

Family support is both one of the best predictors of a child's success in residential treatment and the most important single factor in determining the child's postdischarge adaptation. The author presents a systematic framework for staff in residential programs who may wish to develop parent groups as a means to enhance family support for children in care. (Journal abstract)

The framework described by the author includes: (1) objectives and functions of parent groups; (2) assumptions of group leaders; (3) three design steps for group development; (4) core content elements; and, (5) core processes. Residential programs which seek to develop parent groups must deal with several critical issues. Among these, the mandate of the program needs to be clear to all involved, program goals should be specifically defined and carefully evaluated, and "the staff of the program will need to be firmly convinced of the critical role of parents as partners in the helping and treatment process."

Bernheim, K. & Switalski, T. (1988). The Buffalo Family Support Project: Promoting institutional change to meet families' needs. *Hospital and Community Psychiatry, 39*(6), 663-665.

Key Words: psychiatric hospital, staff training and development, service delivery, evaluation, agency/institutional policy

In 1985, the Buffalo Psychiatric Center began an integrated approach to meeting the needs of mental health patients and their families. Family members were equal participants in the development and ongoing operation of the project. The committee directing the project was composed of five family members, five staff members, and two consultants. The project generated a number of staff training packages, ideas for staff development, and services for families. The committee's working structure was built around four goals: (1) evaluation of family and staff attitudes toward family involvement; (2) staff training and development of new policies; (3) implementation of family-oriented services; and (4) ongoing evaluation and monitoring.

The authors discuss changes in the institution's policies and practices and results of two working groups composed of family and staff members. The authors draw several conclusions from this experience: (1) it is critical that both relatives and staff participate equally in the planning and implementation of initiatives; (2) institutional change is an evolutionary process that requires the gradual development of an ethos--a set of shared values, assumptions, and goals; (3) institutional change is possible; and (4) a substantial influx of new money is not required to establish a family support program.

Bersani, H.A. (1987). *Site Visit to Calvert County, Maryland ARC Family Support Services.* Syracuse, NY: Research and Training Center on Community Integration, Center on Human Policy, Syracuse University.

Key Words: Maryland, site visit, developmental disabilities

The intent of this program is to prevent any person 21 years of age or younger from being institutionalized. The program provides respite, specialized family support, and integrated day care to approximately 50 people with developmental disabilities and their families. The specialized family support component attempts to help parents obtain any service or piece of special equipment which the family sees as needed in order to maintain a disabled member at home. (Author's summary description)

Cooley, E. A., Singer, G. H., & Irvin, L. K. (1989). Volunteers as part of family support services for families of developmentally disabled members. *Education and Training in Mental Retardation, 24*(3), 207-218.

Key Words: volunteers, community

This paper describes a university-based volunteer program for children with developmental disabilities which was implemented as part of a larger family support model demonstration project. Volunteers in the program were paired one-on-one with children and engaged in weekly outings in order to establish friendships and increase the children's opportunity to participate in community activities. Procedures for recruiting, screening, training, and supervising volunteers are briefly described, and program evaluation data are presented. (Journal abstract)

Deal, A.G., Dunst, C.J. & Trivett, C.M. (1989). A flexible and functional approach to developing Individualized Family Support Plans. *Infants and Young Children, 1*(4), 32-43.

Key Words: individualized plans, family systems

A flexible and functional approach to writing and implementing Individualized Family Support Plans (IFSPs) is described. The approach is derived from a needs-based family systems model of assessment and intervention. The systems model and approach to developing IFSP's are designed to enable and empower families to become more capable of mobilizing resources to meet their needs in ways that support and strengthen child, parent, and family functionings. (Journal abstract)

***General Accounting Office (1990). *Respite Care: An Overview of Federal, Selected State, and Private Programs.* Washington, DC: U.S. General Accounting Office.**

Key Words: respite care, survey

"This report is in response to a request by the chairman of the Select Committee on Children, Youth, and Families of the House of Representatives. The purposes of the report are threefold: (1) to provide information on the characteristics, nature, and availability of respite care services; (2) to obtain respite care users' views about the services provided; and (3) to provide suggestions for improving respite care services and enhancing the federal role. The focus of this report is on respite care services that

provide temporary relief to family members and other caretakers of children who may be at risk of abuse or neglect. This includes children who are mentally retarded, behaviorally disturbed, physically disabled, or chronically or terminally ill.

In fiscal year 1988, 25 states were surveyed, which included 111 respite care programs. Six national organizations were also identified, including the Easter Seal Society and United Cerebral Palsy Association, that provide respite care services through 279 of their local chapters in 221 cities of 44 states and the District of Columbia. While little evidence is available on the efficacy of respite care, users found the services beneficial in giving them more time to attend to other family and daily-living activities. Respondents reported that the demand for respite care exceeds the supply available. Several suggestions were offered for improving respite care services, including increasing the amount of information and publicity about available programs, training more providers, and allowing programs to be tailored to individual families' specific needs. State officials and providers also offered several suggestions concerning the government's role in respite care. One was to offer incentives, such as demonstration and matching grants, to the states to focus greater attention on respite care." (From report introduction)

***Glendinning, C. (1984). The resource worker project: Evaluating a specialist social work service for severely disabled children and their families. *British Journal of Social Work, 14*, 103-115.**

Key Words: evaluation, program description, availability of support, parent/professional collaboration, case management

Accumulated research evidence revealed the continued fragmentation of support services for families caring for a severely disabled child; while parents themselves repeatedly reported the lack of a comprehensive source of information and advice. The resource worker project was designed to assess whether the levels and coherence of services to the families of severely disabled children could be improved through the intervention of specialist social workers. The activities of the social workers were extensively documented and multiple methods of data collection were used to evaluate their intervention, in comparison with a matched group of families who continued to receive the normal generic services.

According to a number of outcome measures--for example families use of services, facilities and professional expertise; the incidence and severity of stress among parents; the mental and physical well-being of various family members--changes occurring as a result of the intervention were, apparently, neither large scale or consistent. Nevertheless parents were virtually unanimous in their positive and enthusiastic appreciation of the help and support they had received. The implications of these findings for the evaluation of social work interventions are discussed; and attention is drawn to the importance of evaluating interventions of this kind, as the long term support of families with severely dependent members is likely to place increasing demands on social work and social services resources in the future. (Journal Abstract)

Goerge, R.M. & Osuch, R. (1992). The effect of cash assistance on families of children with severe emotional disturbance or developmental disabilities: An evaluation of the Family Assistance Program in Illinois. In Kutash, K., Liberton, C.J., Algarin, A. & Friedman, R.M. (Eds.) *A System of Care for Children's Mental Health Expanding the Research Base*, pp. 265-270. Tampa, FL: Research and Training Center for Children's Mental Health, Florida Mental Health Institute, University of South Florida.

Key Words: Illinois, cash subsidy

Cash subsidy programs for families of children with disabilities are gaining support both in theory and practice as a way to maintain the child in the home. These family centered initiatives are aimed at meeting the specific and unique needs of the families by allowing them greater choice over goods and services. In 1990, Illinois became the first state to provide cash assistance for families of children with severe emotional disturbances and for families of children with developmental disabilities. This report addresses the effects of cash assistance on out-of-home placements and its impact on the family. Policy implications and recommendations for the future are presented. (From chapter abstract)

Hamm, J. (1989). Intensive day treatment provides an alternative to residential care. *Children Today, 18*(5), 11-15.

Key Words: Phoenix Program, day treatment, residential treatment, Illinois

The Phoenix Program--a day treatment center in Moline, Illinois, provides intensive educational, social and mental health services to high-risk teens only a step away from placement into correctional or mental health facilities. With a diversity of services under one roof, Phoenix offers severely emotionally and behaviorally disturbed youth the intensity of a residential treatment program without the need for overnight stays. Families are kept together. (From author's introduction)

The story of a troubled adolescent male is used to dramatize the features of the Phoenix Program. Characterized as the combination of a social service agency and a school, the Phoenix program was established to fill the gap in the youth service network; many teens were being sent to mental health and correctional facilities because there was no local option. The Phoenix Program fills that gap by providing a 4-part day treatment program offering respite care, therapeutic recreation therapy, special education, and at-home counseling.

Heying, K. (1985). Family-based, in-home services for the severely emotionally disturbed child. *Child Welfare, 64*(5), 519-527.

Key Words: emotional disorder, behavioral disorder, aftercare, residential treatment, day treatment, in-home services

The author describes a program serving families of children with emotional and behavioral disorders in their own homes. The program was developed to prevent out-of-home placement of children and the consequent disruption to their families. Two categories of services were offered: 1) use of in-home treatment as an alternative to institutional or foster placement; and 2) aftercare services as a follow-up to residential or day treatment. Criteria for referral, staff and funding resources are discussed.

The author presents the theoretical basis of the program as looking "beyond the individual child for disturbed or suboptimally functioning social systems, with the philosophy that the child...is as much a product of disturbed relationships as a contributor to them." According to the author, the child's family, teachers, and caretakers are all considered "clients." This approach includes assisting families in establishing their own support systems.

Illinois Planning Council on Developmental Disabilities. (1991). *Family Support: A New Way of Thinking*. Springfield, IL: Illinois Planning Council on Developmental Disabilities.

Key Words: developmental disabilities, Illinois, principles

This brochure presents an overview of the eight trial Family Support Programs in Illinois which attempt to meet needs of families of children with disabilities in order to enable such children to remain with their families and avoid institutional placements. Principles of family support are listed, including its focus on whole families and meeting needs within integrated community environments. Innovative approaches of some of the programs currently offered in 45 states are noted. The Illinois program is then reviewed, noting such factors as provision of services to over 150 families, new state legislation, planned stipends to families providing care at home, and direct services to adults to encourage self-supporting independent living. (ERIC abstract)

Karp, N. & Bradley, V. (1992). Family support: A state of the states. *Children Today, 20*(2), 28-31

Key Words: history, survey, support types

The stated purpose of this article is "to present a summary of how family support programs began, how they are working today, and in what direction they should be going." The authors explain the meaning of "family support," provide a state-by-state analysis of family support programs, describe types of supports offered, and outline a set of values desired by families as a guide for the implementation of family support programs. Types of support described are: 1) respite and child care; 2) environmental adaptation; 3) supportive services; 4) in-home assistance; 5) extraordinary/ordinary needs; 6) training; 7) recreation; 8) systemic assistance; and 9) financial assistance.

The authors recommend several key structural components of a system of family supports: 1) local control; 2) central role of case management; 3) parent advisory boards; 4) individualized family support planning process; 5) true decision making in the hands of parents; 6) use of local agencies; 7) an appeal process; and 8) a mechanism for quality assurance.

Kinney, J., Haapala, D., Booth, C. & Leavitt, S. (1988). The homebuilders model. In *Improving Practice Technology for Work with High Risk Families: Lessons from the "Homebuilders" Social Work Education Project*, Monograph Number 6, p. 37-67. Seattle, WA: Center for Social Welfare Research, School of Social Work, University of Washington.

Key Words: service planning, service delivery, crisis intervention, in-home services, family preservation

The authors describe the philosophy, history, and basic components of service delivery and evaluation of the Homebuilders program. The program was established in 1974 "...to prevent the unnecessary out-of-home placement of children in state-funded foster care, group care, psychiatric hospitals and corrections institutions." Services consisted of intensive in-home family crisis intervention and education. The fundamental belief of the Homebuilders program is that "it is best for children to grow up with their natural families."

Other important values and beliefs of the Homebuilders program include: (1) it cannot easily be determined which types of families are "hopeless" and which will benefit from intervention; (2) it is the job of Homebuilders staff members to instill hope; (3) clients are colleagues; (4) people are doing the best they can do; and (5) care must be taken because harm can be done as well as good.

Basic components of the Homebuilders model are: (1) therapist availability; (2) flexible scheduling; (3) location of services; (4) flexibility in services delivered (5) intensity; (6) worker caseload; (7) brevity; (8) limited objectives; (9) staffing; and (10) evaluation. Two case studies are presented.

Knoll, J.A. (1990). Family support: A challenge for the 1990's. *Exceptional Parent*, *20*(4), 28-34.

Key Words: survey, national directory

There have been major efforts to examine and redefine the relationship between families of children and adults with disabilities and all programs, public and private, that provide services. In order to have a clearer picture of what states are doing, the Human Services Research Institute, with support from the Administration on Developmental Disabilities in the U.S. Department of Health and Human Services, has just completed a series of interviews with key parents and professionals in every state. "Family Support Services in the United States: An End of Decade Status Report" is a result of this work. It contains a detailed description of national trends in family supports and a state-by-state summary of family support programs. We are highlighting the major trends in this article. A directory of state family support programs, which includes a brief summary of what each state provides under the umbrella of family support, follows this article. (from introduction)

***Knoll, J.A., Covert, S., Osuch, R., O'Conoor, S., Agosta, J., Blaney, B. & Bradley, V.J. (1990). *Family Support Services in the United States: An End of Decade Status Report*. Cambridge, MA: Human Services Research Institute.**

Key Words: state survey, national directory

There have been major efforts to examine and redefine the relationship between families of children and adults with disabilities and all programs, public and private, that provide services. In order to have a clearer picture of what states are doing, the Human Services Research Institute, with support from the Administration on Developmental Disabilities in the U. S. Department of Health and Human Services, has just completed a series of interviews with key parents and professionals in every state. This report is a result of this work. It contains a detailed description of national trends in family supports and a state-by-state summary of family support programs. (from author's description)

The report consists mainly of three detailed tables with summary information about family support in each state. A fourth table provides a taxonomy of family support. Table 1 contains general information about family support services in each state, including the nature of supports offered, type of program, eligibility criteria, limitations on benefits, allowable services, families served, and current funding. Table 2 lists selected family support practices in each state, including legislation, financial assistance, services, fee for services, respite only, medicaid waiver, pilot project, and number of families. Table 3 is a state-by-state breakdown of 38 services provided or covered by state family support programs.

Mikkelsen, E.J., Bereika, G.M. & McKenzie, J.C. (1993). Short-term family-based residential treatment: An alternative to psychiatric hospitalization for children. *American Journal of Orthopsychiatry, 63*(1), 28-33.

Key Words: residential treatment, short-term, hospitalization

A short-term treatment program designed as an alternative to psychiatric hospitalization for children and adolescents is described. The program utilizes a multidisciplinary professional team and specially training individuals (mentors) who work with the child and the child's biological family in the context of a mentor's home. Admission, discharge, and follow-up data on a group of patients are reported. (Journal abstract)

***Murray, J.D. (1992). *Analysis of Outcome Data of the Finger Lakes Family Support Program*. Mansfield, PA: Rural Services Institute, Mansfield University.**

Key Words: Finger Lakes, outcome measures, program evaluation

"This report summarizes an analysis of the program evaluation data collected for the Finger Lakes Family Support Program begun in late 1990 under the auspices of the Elmira Psychiatric Center, Children and Youth Outpatient Department. The program was established to provide families of children with emotional problems information, support, and brief respite care." Five measures were administered to the parent/participants that were pre-existing published scales: (1) The Revised Behavior Problem Checklist (BPC); (2) The Parenting Stress Index Short Form (PSI/SF); (3) The Family Support Scale (FSS); (4) FACES III; and (5) Internal-External Locus of Control (I-E). Two supplementary questionnaires were developed by Rural Services

Institute (RSI) at Mansfield University in Pennsylvania: (1) The Family Information Form; and (2) The Comprehensive Evaluation Form.

"This data analysis only speaks to the data that were collected by paper and pencil and forwarded to the Rural Services Institute. It does not contain any first hand data collected in direct contact with the program. The data reviewed here, while limited in numbers and depth, suggest positive effects of the program. Clearly, the parents that "stuck with" the program rate it very favorably. It is also clear that the program responded to needs in a very stressed group of families and parents and that the program was seen as meaningful and useful in response to those needs. In meeting its primary goals of parent support and respite care the program appears to have met its objectives."

Rubenstein, J., Pilon, B.A. & Dlin, R. (1981). The use of family support systems in the treatment of emotionally disturbed children. *Canada's Mental Health, 7-8*, 26.

Key Words: emotional disorder, parent-to-parent support, social support network

The authors describe the Parent-Therapist Program, a family support system designed to assist foster parents in providing care and treatment for children with severe emotional disturbances. The support system is modeled after the functions that a cohesive extended family might serve for its members. The program brings together five "unrelated, healthy, nuclear families" who are each responsible for the care and treatment of a child who is placed in their home. The individual nuclear families are encouraged to function as an extended family, with primary responsibility for the child in their home, and secondary responsibility for each of the other children being cared for by "extended family" members. The authors explain, "The extended family group operates as a functional unit, with the group as a whole sharing obligations and responsibilities for every child treated in the home of one of its members." In addition to informal support which extended family group members provide each other, the extended family members meet weekly as a group with their clinical supervisor for mutual support and shared problem solving. Each nuclear family thus serves as "parent-therapists" for the other families.

The authors discuss several functions of social networks: (1) emotional support; (2) task oriented assistance; (3) communication of expectations, evaluation and a shared world view; and (4) access to new and diverse information and social contacts. Other topics considered are the relationship between program supervisors and parent-therapists, training of parent-therapists, and the importance of mental health workers considering the significant role social support networks play in the lives of their clients. Brief case examples are also provided.

Shoultz, B. (1993). *Like an Angel that Came to Help Us": The Origins and Workings of New Hampshire's Family Support Network*. Syracuse, NY: Center on Human Policy, Syracuse University.

Key Words: New Hampshire, support network

This report reviews the history of family activism in New Hampshire, the activities of the Task Force on Family Support, and the establishment of a Family Support Network consisting of a Family Support Council in each of New Hampshire's twelve regions for serving people with developmental disabilities. This report also describes the workings

of the Councils and the Network, raises issues for discussion, and concludes with lessons to be drawn and implications for other states. It is based on document review, interviews with key players, and participant observation. (Author's report overview)

Several lessons are drawn from the New Hampshire experience with family support: (1) develop a clear vision and principles; (2) build a constituency; (3) take into account the political and social context; (4) recognize that a history of collaboration between state administrators and parents is helpful; (5) put parents in a position of leadership; (6) do not compromise on important issues; (7) pursue goals when the constituency is ready for it; (8) value inclusiveness; (9) perform careful research; (10) promote state flexibility which allows for regional differences; (11) use the community as a rich resource; and (12) build a family network around what could be just a new or expanded category of service.

***Singer, G.H.S., Irvin, L.K., Irvine, B., Hawkins, N. & Cooley, E. (1989). Evaluation of community-based support services for families of persons with developmental disabilities. *Journal of the Association for Persons with Severe Handicaps, 14*(4), 312-323.**

Key Words: evaluation, community-based, developmental disabilities

This article presents an evaluation of a multi-element parent and family support intervention for parents of school-aged persons with severe disabilities. Using an experimental design, we compared two randomly assigned groups of parents: one group received a modest level of support consisting of respite care and case management, and the second group received an intensive intervention that consisted of stress management and parenting skills training, support groups, and additional community-based respite care. Separate MANCOVA analyses were conducted for mothers and fathers. Mothers showed significant improvement on measures of depression and anxiety. Further analysis of the data revealed that a significantly greater number of intensive support group members also achieved clinically significant improvement on measures of anxiety and depression. Fathers participated in smaller numbers than mothers. A power analysis revealed large treatment effects for fathers as well as mothers although, due to the small sample size, the results for fathers were significant at $p = 0.07$. Analyses of 1-year follow-up data revealed that treatment gains maintained for mothers. We discuss the results and limitations of this study in light of current efforts to create family support services nationwide. (Journal abstract)

Walker, P. (1988). Family supports for children with severe disabilities and chronic illnesses in Maryland. In *Resources on Supporting People with Extensive Health Needs in the Community*, pp. 20-44. Syracuse, NY: Research and Training Center on Community Integration, The Center on Human Policy, Syracuse University.

Key Words: health, chronic illness, Maryland, community integration

This report focuses on some of the positive practices in Maryland in family supports, especially for families with children who have severe disabilities and chronic illnesses. It is based on visits to three sites selected by a subcommittee of the Maryland Developmental Disabilities Planning Council: the Family Support Program at The Kennedy Institute in Baltimore, the Coordinating Center for Home and Community Care (CCHCC), and SKIP (Sick Kids Need Involved People). These visits, conducted as part of the work of the Community Integration Project in Maryland in June 1987,

included interviews with program staff and visits to families who receive assistance from these programs. The purpose of the site visit was not to evaluate services, but to identify and document good practices in supporting children with extensive health needs in Maryland. A brief description of each of the sites is presented, followed by discussion of the key family support issues and practices that were identified. (From author's introduction)

***Zimmerman, S. (1984). The mental retardation family subsidy program: Its effects on families with a mentally handicapped child. *Family Relations, 33*, 105-118.**

Key Words: program description, evaluation, research, developmental disability, family caregiving, family functioning

Findings from a telephone survey of a stratified random sample of families receiving a financial subsidy to enable them to care for their severely mentally retarded child at home indicate that although the subsidy does what planners intended, one-half the families (n = 19) eventually plan to place their child out of the home. Influencing variables were mother's age, mother's employment status, family size, and the mentally retarded child's developmental progress. Such findings imply that the Subsidy Program, like all such programs, cannot be expected to overcome strong countervailing family influences. Therefore, for maximum impact, family influences should be taken into account in the design and implementation of policies and programs that depend on families for their outcomes. This study, by illustrating the importance of family variables for thinking about policies and programs affecting families, contributes to the literature on family policy and family policy studies. (Journal abstract)

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An Annotated Bibliography

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